DOCUMENT RESUME

ED 322 303 CE 055 284

AUTHOR Clare, Mariette
TITLE Developing Self-Advocacy Skills with People with Disabilities and Learning Difficulties.
INSTITUTION Further Education Unit, London (England).
REPORT NO ISBN-1-85338-202-7
PUB DATE 90
NOTE 170p.; Appendix F will not reproduce well.
AVAILABLE FROM Information Centre, Further Education Unit, 2 Orange Street, London WC2H 7WE, England (8.00 pounds).
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC07 Plus Postage.
DESCRIPTORS Adolescents; Adults; *Advocacy; Agency Cooperation; Articulation (Education); *Disabilities; Educational Resources; Foreign Countries; *Institutional Environment; Learning Disabilities; Personal Autonomy; Policy Formation; *Portfolios (Background Materials); Program Evaluation; *Special Needs Students; Staff Development; Student Centered Curriculum
IDENTIFIERS *United Kingdom

ABSTRACT

This document is intended for people in education and training, health services, social services, and volunteer organizations who are committed to empowering people with disabilities and learning difficulties. It sets self-advocacy within the context of achieving adult status in the United Kingdom, offers a theoretical framework for professionals interested in beginning this work, describes how portfolios can be used with people with a wide range of disabilities, analyzes the experiences of a group of workers from various settings, and summarizes institutional and professional implications of self-advocacy work. Sections included in the document are as follows: introduction, aims and objectives; planning and resources; implementation; monitoring and evaluation; the key workers; and a checklist for practitioners covering policy, resources, staff development, support for staff, the environment, regulations, sharing power, learner-centered programs, negotiation and choice, autonomy, risk taking, progression, interagency work, monitoring, and evaluation. Appendices include a description of the aims and objectives of the project, a list of steering committee members, an explanation of how the case studies and key workers were identified, 11 brief case studies, and 3 sample portfolios. A bibliography listing 125 sources concludes the document. (CML)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Developing Self-Advocacy Skills
with People with Disabilities and Learning Difficulties

Mariette Clare

ISBN 1 85338 202 7

© Further Education Unit (FEU) 1990

Reproduction in whole or in part of the contents of this publication is authorised for all non-commercial educational purposes, provided the source is acknowledged. Copies made for such purposes should not be recorded as part of any licensed copying scheme. All rights reserved with regard to commercial reproduction of the contents.

RP 449

Printed by J.E.C. Potter & Son Ltd., Stamford, Lincs.

Acknowledgements

Special thanks are due to the case-study workers and their institutions for their hard work and support during the course of the project. They were:

Aston Hall Continuing Education Centre

Broadview FE Unit, Leicester

Cedars Rehabilitation Unit, Nottingham

Chesterfield College of Technology and Art

Community Accommodation Project, Leicester

Community Mental Handicap Team, Lincoln

Newark FE College

Nottinghamshire Social Services Team for Deaf People

North Nottinghamshire College of FE

Rathbone Society, Coalville

Riverside Resource Centre for Disabled People, Towcester

South Field College of FE, Leicester

Karen Beggs; Gary Bland; Lynne Don; Brenda Edwards; Jaqui Fenwick; Branka Gormley; Karen Jacquet; Lisa Mulcahy; Dimity Quinn; Loretta Smith; Peter Towner; Richard Williams; Saskia Williams.

Thanks are also due to all members of the Steering Committee for their guidance and advice, and also to the staff at EMFEC (East Midlands Further Education Council), particularly the reprographic department for their efficiency and speed, and most of all Jean Wortelhock for her calmness and competence.

John Nieto of North London College, formerly of ILEA FHE Curriculum Development Project, gave invaluable help on Portfolio Preparation.

Template for Letters group

Portfolio photographs provided and re-enacted by friends and relatives of project officer: Nathaniel Bennett; Michael O'Shaughnessy; Anita Mitchell; Helena Mitchell; Pat Kirkham; and students and lecturers of Leicester Polytechnic.

FURTHER EDUCATION UNIT

The Further Education Unit (FEU) was established by the Department of Education and Science to give guidance and support to the further education system. FEU advocates and seeks to make possible a more co-ordinated approach to curriculum development, in suport of its remit to promote, encourage and develop better learning opportunities in further education. For more information, please contact:

Information Centre,
Further Education Unit
2 Orange Street
London WC2H 7WE
Tel: 01-321 0433 ext. 256

REPLAN

- REPLAN is a DES programme to improve, increase and promote the development of quality educational opportunities for unemployed adults.

- Further information about REPLAN can be obtained from:

  - Pat Gale (FEU) Tel: 01-321 0433
  - Tony Uden (NIACE) Tel: 0533 551451
  - Adult Training Promotions Unit (DES) Tel: 01-934 0888

CONTENTS

Foreword

Section 1. Introduction

Origins of the project 1
Background 2
The transition to adulthood 3
Barriers to adult status 4
The position of young disabled people 5
Equal opportunities 5
Further, adult and continuing education and unemployment 6
New trends in post-16 education 7
Portfolio preparation and the accreditation of prior experiential learning 7
The principles and practice of advocacy 9
The changing role of professionals 10
Theories and frameworks 10
Reviewing the literature 12
Good practice 12
A model for developing self-advocacy work 13
Working definitions 14
A working definition of portfolios 16
Introducing the key workers for the case-studies 17

Section 2. Aims and objectives

The relationship to vocational preparation 23
Professional and human resources 23
The paradox of professionals and self-advocacy 24
Dealing with emotional distress 24
Choice and consent 25
Raising learners' expectations 26
Conflict with colleagues 26
Taking on an advocate's role 27
Imposing standards 27
Working with parents 28
Professional responsibilities 29

Section 3. Planning and resources

Self-advocacy and portfolio preparation 33
Identifying limitations and resources 34

Negotiating with the learners 35
Taking care 37

Section 4. Implementation

Paradoxes of reporting self-advocacy 41
Reading the case-studies 43
Managing change 45
Making links 45
Working with other professionals 47
Negotiation 51
Choices 1 55
Choices 2 59
Adult roles 62
Sharing information and skills 65
Working with mistakes and disappointments 71
Taking risks 74
Extending the professional repertoire 80
Boundaries and disclosures 83
Summary of key characteristics of successful work that arose from the project 86

Section 5. Monitoring and evaluation

Record keeping 91
Transition towards adulthood 93
Portfolio preparation 98
Portfolios as process 101

Section 6. The key workers

Curriculum change in education 103
Staff development 103
Practice in social work and voluntary organisations 104
Job specification and selection procedures 104
New initiatives 104
Key workers' self confidence 105
Unexplored issues 106

Section 7. A check-list for practitioners

Policy 109
Resources 109
Staff development 110
Support for staff 110
The environment 111
Regulations 111
Sharing power 111
Leaner-centred programmes 112
Negotiation and choice 112
Autonomy 113
Risk taking 113
Progression 114

Interagency work 114
Monitoring 115
Evaluation 115

Appendix A. Aims and objectives of the project 117

Appendix B. The Steering Committee 119

Appendix C. Indentifying the case-studies and key workers 121

Appendix D. Self-organising associations of people with disabilities 123

Appendix E. Case-studies 125

A. Anne 125
B. Bruce 127
C. Chris 128
D. Debbie 130
E. Elena 132
F. Frances 134
G. Gayle 135
H. Harriet 138
I. Ivor and Isabel 139
J. Jane and Jenny 141
K. Kevin 143

Appendix F. Sample portfolios

1. Patrick: Case-study A 147
2. Sarah: Case-study D 152
3. Stuart: Case-study C 158

Bibliography 162

Foreword

Even the most sensitive professional works within a set of largely unquestioned, implicit assumptions about their role and the needs of the people with whom they work.

In this important report, Mariette Clare looks behind the word 'empowerment' and identifies the fundamental changes that professionals must undergo if they wish really to support the autonomy of learners. She describes the discoveries made by her group of key workers as the project progressed; discoveries that were about the potential of their learners, but also about themselves.

Not every professional is ready for this rigorous work; those who are already experienced will acknowledge the need, described within the report, for the setting of a proper professional framework, with clear line accountability, supervision and the support of informed managers. The development of self-advocacy skills cannot be carried out in an amateur, *ad hoc* way; it must be as carefully managed as other aspects of our work, and those undertaking it are to be accountable for what they do and must be offered appropriate support.

Once this framework is in place, exciting and rewarding work can be done, whether it is someone with profound disabilities saying 'no' for the first time or a person with a physical disability moving into their own home.

The 'shift in power' between professional and learner is also discussed in other FEU publications, notably the *Working Together?* series with which this project was closely associated. *Developing Self-Advocacy Skills* is a powerful demonstration of that delicate process.

Pat Hood
Development Officer

Section 1. Introduction

There is an increasing demand from people with disabilities themselves that they should be enabled to take a full and active part in all aspects of social life. In particular, disabled people are insisting on their right to services that meet their needs as they themselves define them. Self-advocacy is a key aspect of this developing awareness. It emphasises the need for people with disabilities to know their own rights and, as importantly, for proper attention to be paid to their experiences, opinions and ideas. The research project described in this report, 'Developing Self-Advocacy Skills with Unemployed, Disabled Adults', is a contribution to the professional responses to these welcome trends. In particular, it took the concept of portfolio preparation, and investigated its usefulness in helping disabled learners to develop and practise self-advocacy skills.

Although the learners and their empowerment were at the heart of the project, this report focuses not on them but on the professionals who work with them. Too often it is the adult learners, disabled or otherwise, who are assumed to be the problem. This report takes the view that disabled people themselves are potentially the best experts on themselves and disability, and that what is required of professionals is scrutiny of their own practices and the ways in which they are disabling. The report describes the consequences to professionals of putting the learners, their rights and goals at the centre of a learning programme.

Origins of the project

The East Midlands Further Education Council (EMFEC) provides the focus for the regional REPLAN Special Needs Group. In 1986 this group had already recognised the particular difficulties facing disabled adults, especially in their attempts to secure employment, acceptable living conditions and an independent life. The promotion of self-advocacy skills was therefore identified as a means by which education could support disabled people in gaining more control over their own lives.

FEU's work in the field of special educational needs for those with learning difficulties had also increasingly included self-awareness, decision-making, rights and responsibilities and communication skills as part of the curriculum. All these are important elements in self-advocacy. (FEU 1982;1983;1984;1986) In particular the FEU report *Transition to Adulthood*, based on research carried out at the Work Orientation Unit,

North Nottinghamshire College of Further Education, and the international work of the OECD/CERI projects in the same field (Fish, 1986; Kelly-Laine, 1988), all emphasise the lack of opportunities for young people with special needs. All studies of the key transitions for disabled young people from childhood to adulthood highlight not only the limited opportunities available, but the confusing array of benefits, regulations and agencies.

> Support services are complicated, piecemeal, inflexible, insecure, and idiosyncratic, and often limit users' lives or result in unnecessary institutionalisation. (Fiedler, 1988)

To all these considerations was added the need for disabled people to be pro-active if they were to become the dynamic consumers implicitly required by the Disabled Persons Act (1986) and by the Griffiths Report (1988).

The EMFEC Special Needs Group was concerned to combine these approaches with elements from the conceptual framework contained in *Adult Unemployment and the Curriculum*, (Watts and Knasel, 1985) and with REPLAN's expertise in restoring a sense of self-worth to, and opening doors for, unemployed adults. *Portfolio Preparation and the Accreditation of Prior Experiential Learning* (APEL) (Evans, 1987) indicated yet another route for the empowerment of learners. Funding was therefore granted to EMFEC by FEU/REPLAN to establish and manage a project that drew together all these threads. This became the project described in this report. A project officer was appointed in May 1988 and the project ran from 1 September 1988 to 31 August 1989. Details of the project's aims, membership of the Steering Committee, and intended outcomes can be found in Appendix A.

Background

The work of this project has greatly benefited from being able to draw on experiences from a number of parallel initiatives and general developments in professional practices within a variety of disciplines. The closure of large residential hospitals has encouraged the growth of client-led approaches within Health Authorities. Professionals from departments of social services and voluntary organisations are also increasingly adopting client-centred ways of working, such as individual programme planning. These methods seek to base services on individually identified needs, rather than on generalised provision into which disabled people are then expected to fit. Shared action planning is another example:

> ...it focuses outward from the individual in working for change, rather than inwards. Instead of creating a picture of the individual with a list of needs that have to be met by others, it looks at what needs to happen to achieve shared goals. The emphasis is on self-advocacy and on creating opportunities for normal life-styles and relationships. Thus it takes the best parts of the IPP process but it goes one step further in

ED322303

Developing Self-Advocacy Skills

with People with Disabilities and Learning Difficulties

CE055284

FEU R

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Love

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

BEST COPY AVAILABLE

helping to redress the balance of power between the professional and user. (Pitt, 1987)

This focus on individuals also emphasises the desirability of inter-agency co-operation and of inter-disciplinary team work. In this way delivery of services can be both dovetailed with personal goals and efficiently managed.

The OECD/CERI's extensive study of the education of young people who are disabled has also been an important resource. This work represents the international shift in perspective away from what it describes as 'protective, lifelong support systems' towards the understanding that autonomy, responsibility and risk-taking are essential elements in becoming an adult. The consequences of applying these values and principles have been the object of the series of studies called *Working Together?* that form the UK contribution to the OECD/CERI Programme. In particular this project shares common objectives with the programme's studies carried out by Griffiths and Wertheimer.

There is, therefore, a set of concerns and objectives shared by a very wide range of professionals and disciplines. The seminal role of disabled people themselves has already been indicated. Similar trends can also be identified in the educational world where questions of open access, flexible learning and new forms of accreditation all indicate profound changes in attitude and practice. A brief description of a number of developments which have influenced this project is given below.

The transition to adulthood

Whatever their ethnic background, gender or class, the transition of young people in the Western world, from childhood to the status of adulthood, is constructed through changes in at least four major areas. These are:

1. Personal autonomy and independence from parental control.
2. Economic self-sufficiency, usually through employment.
3. Citizenship: legal responsibilities and rights, voting rights, access to community resources, etc.
4. New relationships outside the family of origin, especially sexual and marital relationships. (Fish, 1986; Cockram and Beloff, 1976)

These are essentially changes in power and status, and are accompanied by significant changes in self-concept. Individuals are able to find a new identity as adults. Such changes, however, do not arise simply by the fact of the child growing older. Deeply concerned with psychological or subjective change as it is, the transition to adulthood is nevertheless a social enterprise. Each individual does not spontaneously begin the struggle for adult status on her or his own; the impetus arises from the

expectations and demands created by the combination of adolescent peer groups and the adult world. Such expectations and demands are not only recognised through direct personal interactions with others but are also experienced through the messages received from society as a whole: advertising, TV and radio, records, videos, films and books all create images of what it means to be adult. Although this implies that some individuals may be denied access to those social elements in adolescence that smooth the path to adulthood, it also suggests that such deficiencies can be made good at a later stage. (Card, 1983; Wertheimer, 1988)

It is essential that the expectations and demands created for young disabled adults should not be different from those for the rest of society; the goals of transition should be the same for all. Unless these same opportunities and pressures exist for children with disabilities, they will be further handicapped and disadvantaged. There is increasing evidence that, in the right circumstances, adult status can be made available and attained by any individual, whatever their disability.

Barriers to adult status

There are, of course, some obvious barriers to the achieving of adult status by disabled young people, especially when the social factors are considered. These include:

- Stigma and prejudice: the messages received from the social world by young people with disabilities largely tell them that people like themselves do not exist in the eyes of society, except as objects of pity and concern. There are few films, books or other cultural forms in which people with disabilities are seen to be adults and from which inspiration can be drawn. They may also meet with actual embarrassment, hostility and rejection. It requires unusual inner strength to sustain a sense of self-worth and dignity in a society that systematically discredits your very being. (Goffman,1968, 1971; Campling, 1981; Wertheimer, 1988; Sutherland, 1981; Thomas, 1982)
- Institutionalisation: loss of personal effectiveness, purpose and self-esteem are all well-documented consequences of having to live in an institution. Although such self-subordination is essential for survival under certain conditions, it is wholly disabling as a strategy for living in the real world. There are still substantial numbers of disabled people who suffer in this way from earlier policies of segregation. (Shearer, 1981; Williams, 1978; Chamberlain, 1982)
- Education and access to community resources: too often separate provision has meant inferior education and exclusion from important forms of accreditation and other services. Specialised provision also removes young people from contact with their able-bodied peer group and often denies them knowledge of common social issues, together

with the opportunity to develop commonplace social skills. (Warnock, 1978)

- Employment: there is a variety of factors that tend to exclude disabled people from employment, besides the general features outlined above.These are:
  - lack of information and support for employers;
  - lack of legislative intervention, e.g. enforcement of quota systems;
  - the state of the labour market;
  - a benefit system that creates financial risks for those attempting work and penalises those who might wish to work part-time. (Griffiths, 1989; Walker, 1982, 1985)

The insights and practices discussed in the body of this report are best understood within this general social framework.

The position of young disabled people

It is now widely accepted that it is not the presence of a disability that creates handicap; individuals are handicapped through the failure of society to adapt to their needs (Fish 1989). As has been indicated, too often young disabled people are not able to share the experiences available to their non-disabled peers. Lack of transport as well as physical dependence may pre-empt their taking part in a range of social and educational activities. Such circumstances may prevent them from choosing their own friendships, shopping for themselves and establishing an identity outside the control of their home or school setting, all of which are part of establishing a sense of autonomy. The isolation and depression of disabled school leavers is an unfortunate reality. Parents of young disabled people also have a difficult role to fulfil. There are not only the issues of autonomy and dependence to resolve, but pragmatic questions of the adequacy of services, the availability of employment and the additional social and physical risks to be faced by young disabled people. (Anderson, 1982; British Psychological Society, 1989; Chapman, 1988; Glendinning, 1983; Mittler and McConachie, 1983; Roskies, 1972; Thomas, 1988; Fish, 1989)

Equal opportunities

It is not only disabled people who find themselves marginalised in society; many other disadvantaged groups have sought to redefine themselves, and much work has been developed in supporting them. This is not to suggest that disabled people have identical concerns with such groups as members

of ethnic minorities, the working class and women. Indeed, disabled people themselves are a far from homogeneous group, belonging to different groups according to their gender, race, class and sexual orientation. However, members of all such oppressed groups share a common need to define who they are for themselves, to acquire non-traditional skills and to make demands on the society that excludes them. Equal opportunity policies and the practical actions which they encourage are among the means developed to facilitate such goals. (Arora, 1985; Brandt et al, 1987; FEU, 1985; REPLAN, 1987, 1988)

Further, adult and continuing education and unemployment

Disabled adults are frequently unemployed, and their lives share many of the dispiriting features common to this experience. The substantive work accomplished by the DES-funded initiative, REPLAN, identifies what can be achieved by education in this area, and also its limitations. The benefits offered by a range of post-16 education are varied, and may be particularly appropriate for disabled people. The possible benefits include:

- a recovery of self-confidence
- social contacts and companionship
- new skills and knowledge
- structure and purpose to everyday life
- student progression onto accredited provision which can provide 'real qualifications'
- the recovery of old skills
- an improved quality of life

Adult education can be a resource for all unemployed people, whether disabled or not. However it does not necessarily:

- result in waged employment;
- provide an income;
- improve housing conditions;
- solve transport or mobility problems.

It is a basic tenet of further, adult and continuing education that those benefits which do derive from participation in it should be made available to all groups within the community, especially those that have been excluded from other educational provision. The essential characteristics of such provision are well attested; those that concern this project are that educational provision for disadvantaged adults must:

- be student-centred. It must respect the present situation and knowledge of the learners;
- offer a negotiated curriculum. Both the goals of learning and the means by which they are reached should be agreed in partnership with the student;
- be sensitive and flexible. It must recognise the constraints and difficulties in people's lives and adapt to meet their needs. (Groombridge, 1987; Johnston, 1987; McDonald, 1984; Fraser and Ward, 1988)

New trends in post-16 education.

The last decade has seen a decisive shift away from course-based and syllabus-led provision in post-16 education. The growing emphasis on individualised programmes of learning has required different styles of organising and delivering the curriculum. Through CPVE and more latterly NVQs, vocational qualifications are being offered through a modular framework. In order to meet diverse learner needs, many FE colleges have adopted workshop approaches. These have been complemented by provision which is offered through open and distance learning methods, thus serving to increase the options open to learners. Accordingly, attendance patterns have changed since students are no longer required to attend as regulated by a timetable. Formal registration systems are no longer appropriate, so different methods of recording attendance, learning and achievement have been sought. These changes in organisational approach are matched by trends towards formative student recording of achievement which helps to facilitate modular accreditation. The summative record of achievement has provided a mechanism by which learners may describe themselves to future employers, trainers and other providers of education. Records of achievement include statements regarding learning which has taken place within the formal educational environment; evidence of informal learning and also, as in CPVE, examples of actual work. They therefore have great similarity with portfolios produced by artists and art students as evidence of suitability for further study and employment. They allow learners to accumulate credits at their own pace and according to their own needs. The overall effect of this is to validate the learners' competence, however it is acquired. (FEU, 1986, 1987, 1988, 1989; Hall, 1987; HMI, 1989; NCVQ, 1989; Paine, 1988)

Portfolio preparation and the accreditation of prior experiential learning

Although these concepts have their origin in the USA, they fit well into the developing UK scene. In the USA they were a means by which adults who

lacked all formal educational qualifications, including a high school diploma, could receive formal credit for the skills and knowledge they had gained in their adult lives. The concept has been transferred to the United Kingdom where it is becoming established (a forthcoming UDACE paper deals further with this). ILEA's FHE Curriculum Development Project was among the pioneers in this field and this project was able to draw upon their expertise and experience.

The essential stages in preparing a portfolio are:

- recall of experience
- identification of learning
- collection and presentation of the evidence of learning
- assessment of the portfolio
- presentation to an accrediting body

The first three stages in particular are relevant to the aims of adult education with disabled and unemployed adults. People with disabilities are often made the objects of expert knowledge, and their own experience is consequently disallowed. Portfolio work offers an opposite approach. It is:

> ...a way of converting previous 'failures' into success stories by searching for what has been learned from previous experiences, whatever they were. It has a positive and not a negative stance towards people's learning. (Evans, 1987)

This is also akin to a key feature of self-advocacy; the recognition that only disabled people have direct knowledge and experience of what it is like to be disabled and to be the recipients of services. As Ken Tice, an American with learning difficulties, says:

> '...I think it's important that I help other people stick up for their rights. Since I'm a consumer, I know what it's like on the inside of the situation. We know what's going on in the group homes.' (Quoted by Mohr, 1983)

Portfolio preparation offers the possibility of drawing out and respecting the ways in which people with disabilities know 'what's going on'. By paying attention to this knowledge and experience, disabled adults gain in dignity and control, and professionals are enabled to learn and develop. Questions about how such knowledge might be assessed and by whom, and about what competence it demonstrates, are less easy to answer. The original aim of portfolio preparation was access to further or higher education. It became part of the objectives of this project to establish if there were other uses for finished portfolios. (Evans, 1987; Nieto and Li, 1987)

The principles and practice of advocacy

The last decade has seen the growth of a variety of forms of advocacy in connection with disabled people. In this sense, advocacy means to speak and act, persuasively or forcefully, on behalf of someone's rights and interests, whether these are your own or someone else's. At least three forms of advocacy are commonly identified.

Citizen advocacy is the voluntary involvement of a member of the public in the life of a disabled person, usually someone who is institutionalised and has no other contact with the 'outside' world. Citizen advocates undertake to become the resident's friend. Their role is to find out what his or her wishes are, to speak to members of staff on the resident's behalf and to represent him or her on such occasions as case conferences. At the minimum they try to ensure that the person is treated in such a way as citizen advocates would accept for themselves.

Closely allied to this is **legal advocacy** which does not necessarily involve a personal relationship. Volunteers who become advocates are independent members of the public, who are therefore able to monitor the legal and financial affairs of disabled people who are unable to do so for themselves. This is a check against their exploitation by institutions or, indeed, other members of their family.

Self-advocacy is perhaps the best known of all these approaches, and its most highly developed form is probably the international People First — a self-advocacy organisation for people with learning difficulties. Formally constituted self-advocacy groups share the thinking behind **citizen** and **legal advocacy** and lay strong emphasis on the necessity for their independence from professionals. Unpalatable though it is to some professionals, it has to be accepted that it is the misuse of their power to control and define the lives of disabled people that has made self-advocacy such an imperative need. (Bicklen, 1986; Chamberlain, 1988; Cooper and Hersov, 1986; Crawley, 1988; Kings Fund, 1984; Lawrence, 1982; Notts. Coalition of Disabled People; People First of Washington, 1986; Sang, 1983; Welter, 1978; Williams and Shoultz, 1982; Wolfensberger, 1983; Worrell, 1988)

Besides these important initiatives, mainly concerned with people with learning difficulties, there have been, in the USA and the UK, parallel movements run by disabled people themselves, particularly those with physical disabilities and increasingly those with sensory impairment. The deaf community, for example, is particularly emphatic in its insistence on the rights of deaf people as a linguistically defined minority. Often referred to loosely as the 'disability movement', there is a developing network of organisations who can justly claim to speak with the voice of the consumer. Pioneering ventures such as the Derbyshire Centre for Integrated Living are still rare examples of the sort of services that disabled people would choose to develop. (Kyle and Pullen, 1988; Sutherland, 1981; Notts. Coalition of Disabled People)

The Care in the Community policies have given an added impetus to these activities. For the first time there is the opportunity for disabled people to represent themselves within the planning structures for the joint planning and financing of services. Although there are grounds for anxiety that this is a token gesture, it may still be an important step towards making professionals accountable to service users. (Audit Commission, 1986; Brandon, 1983; Charnley et al, 1987; DHSS, 1983, 1985, 1986; Griffiths, 1988; Harper, 1988; Lavender, 1985, 1988; Renshaw, 1987; Winckler, 1987)

The changing role of professionals

These various initiatives combine to influence professional practice and self-definitions. Staff from a range of disciplines and agencies share many common objectives and principles, although there are differences in how they are able to implement them. There has been a discernible shift in priorities among professionals. In education, this can be seen in an increased emphasis on integration, particularly among school-age children, and on issues of access for the post-16 age group. The intention is to ensure that disabled people can share in the opportunities open to their peers, and that there should be no difference in the goals set for them. Professionals in health and social services share these concerns. An influence here has been the work of Wolfensberger, who provides a rigorous method for the evaluation of services according to the values of 'normalisation'. This is the principle that all disabled people, whatever their condition, are entitled to the same socially valued amenities as the rest of society. All aspects of life such as accommodation, employment, transport, leisure, education, medical care and financial support are included. As an evaluative tool and as a guide for action it has served to highlight the inadequacies of services for handicapped people, and has given legitimacy to demands for their improvement. (George, 1984; Males, 1985; Milroy and Henney, 1985; O'Brien, 1981; Pitt, 1987; Stanley, 1985; Wolfensberger and Thomas, 1983)

Theories and frameworks

Action research

Developing self-advocacy skills, and using portfolio preparation with students with special needs, represented new departures in further, adult and continuing education. There was no existing body of professional practice and opinion on which a general survey or other forms of quantitative research could be carried out. This project was therefore an exercise in action research, based on 11 case-studies that were directly initiated, monitored and evaluated by the project staff. No claims can be made that these studies were either typical or that the outcomes were

statistically significant. **This report provides a qualitative and in-depth analysis of practical attempts to test the key hypothesis:** that **self-advocacy skills developed with the help of professionals actually enable adults with disabilities to make changes in their own lives; and that portfolio preparation is a useful tool in attaining this end.**

A range of situations was chosen in order to demonstrate how the same aims and principles may vary in their implementation.

Quantifiable outcomes, such as access to other courses, or changes in employment or living situation, were important in testing the central question. However, any research involving self-advocacy is likely to raise issues about subjective change as well, in both professionals and learners. In order to be of use to other practitioners and to be replicable, some account needs to be given of the detailed tasks, activities, experiences, problems and solutions encountered by the case-studies' key workers. It was hoped to identify the processes that brought about change, and to describe indicators for success and progress that could be generalised beyond the 11 case-studies. The research therefore focused on:

- the key workers and changes in their:
  - attitudes and values
  - personal qualities
  - professional skills
  - perceptions and understandings
  - relationships with others.
  - future plans;
- all the work undertaken connected to self-advocacy and portfolio preparation:
  - objectives of each session
  - planning and negotiation
  - content and delivery
  - liaison with other professionals
  - work with parents/carers;
- the portfolios:
  - the means used to develop them
  - their contents
  - the uses to which they were put
  - their reception by others;

- the learners and changes in their:
  - behaviour, skills and knowledge
  - relationships with others
  - reported self-concept
  - goals
  - life situation.

These four areas were monitored in a variety of ways which included:

- questionnaires
- structured logs and diaries from key workers
- intensive supervision of key-workers
- extended interviews
- use of consultant
- participant observation
- development activities for key workers
- group discussions

Reviewing the literature

The conclusions reached in this report are informed not just by the case-studies, but by other findings reported in the literature. Work in adult education, special educational needs in further education and counselling and personal skills all have much to offer. There is also a small specialism developing in the background and practice of different forms of advocacy. The accreditation of prior experiential learning is also an area of expanding expertise. The framework all this provides is described in the section *General Background*.

Good practice

Contacts were sought among practitioners experienced in self-advocacy issues, particularly those who are members of what might loosely be called the disability movement. Workers in the Advocacy Alliance and from social services, especially those working with people described as 'mentally handicapped', also contributed valuable perspectives, material and organisational insights. A list of names and useful addresses is to be found in Appendix C.

Education might consider working practices that take for granted the need of individual professionals for regular supervision. This can provide essential support for workers in open-ended situations, and can offer the security of professional endorsement should workers ever be called to account for their practice in an innovative or ill-defined area of work.

A model for developing self-advocacy work

Although portfolio preparation might be seen as a particular element, self-advocacy has much wider implications; as a concept it encapsulates a fundamental approach. The key workers all recognised this challenging aspect of self-advocacy, seeing it as a basic principle, closely allied to the question of human rights:

> 'I have always been interested in the rights of the individual.' (Jane)

> '[It] is my fundamental belief and has been ever since I can remember.' (Elena)

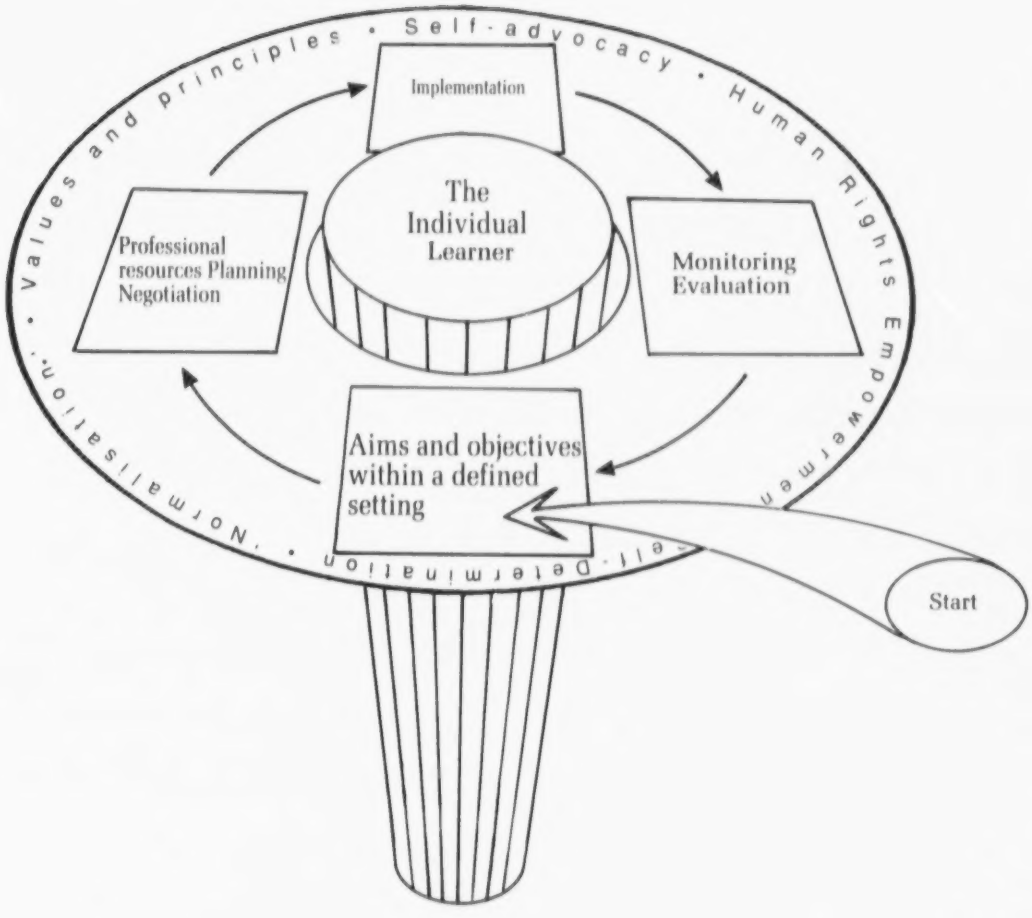
These beliefs were identified as having important and far-reaching consequences for professional practice:

> 'Self-advocacy to me is a very fundamental concept, the principles of which are so basic to our lives that we need to constantly examine the service we provide....How easy it is to contravene people's basic rights by ignorance, by being tired, by trying to be efficient, etc.' (Debbie)

> 'On a personal level it [my interest in self-advocacy] is due to being increasingly "self aware" of my own approach to those "in my care" and my commitment to continually re-evaluate my professional approach.' (Bruce)

The project wanted to preserve this creative tension between the fundamental principle of self-advocacy on the one hand, and the specific and individual needs of the learner on the other. The model framework that emerged is shown in Table 1. The circumference of the diagram represents the over-arching value system of the rights of people with disabilities to self-determination, while at the centre are the particular needs of each individual learner. The ring of linked processes in the boxes closely follows the FEU curriculum model, and is itself encircled by the essential guiding principles. The process of the project focused on putting these guiding principles into action.

Table 1


Values and principles • Self-advocacy • Human Rights Empowerment • Self-Determination • Normalisation •
Implementation
The Individual Learner
Professional resources Planning Negotiation
Monitoring Evaluation
Aims and objectives within a defined setting
Start

* 'Normalisation' asserts the rights of people with disabilities to equality of access to 'socially valued amenities' (Wolfensberger). Services are evaluated through a complex system of criteria which include geographical location and characteristics of the institution such as dress codes, etc., but it can all be summarised in the question: Can people with disabilities do what 'normal' people can do?

BEST COPY AVAILABLE

Working definitions

The key workers needed to agree on some working definitions of self-advocacy, and it was important that they shared common understandings about the guiding values for their work. There also needed to be some consensus about the potential of portfolio preparation so that they could start to define concrete objectives for themselves on a basis of shared and agreed aims.

A working definition of self-advocacy

Although there is some variation in the way self-advocacy is defined by different groups, certain core components can be identified. Among these are:

- **being able to express thoughts and feelings, with assertiveness if necessary**
- **being able to make choices and decisions**
- **having clear knowledge and information about rights**
- **being able to make changes**

As a list, this might suggest a number of competencies that many disabled people appear not to have. It was of central importance to the project to ensure that the appearance of self-advocacy in the curriculum actually enhances the life chances and autonomy of the learner, and is not allowed to become another arena for failure. In order to prevent this happening, professionals need to re-evaluate their own attitudes and practices.

Attitudes

The starting point of self-advocacy is the belief that all human beings have equal value and are deserving of respect. Without this foundation of an affirmative attitude, professionals will, consciously or not, continue to give negative messages to people with disabilities about their own value and competence.

Skills

In second place is the recognition that self-expression — speaking for yourself — is only possible when there is someone else to listen and hear. Indeed, really listening to someone, giving them time, attention and recognition is a key means of according value and respect to another person. There are central professional competencies here that need to be identified and developed.

BEST COPY AVAILABLE

From this perspective, self-advocacy can be seen as a relationship in which it is the professionals' responsibility to:

- invite and value the learners' self-expression;
- offer choices and develop decision-making skills;
- act as an information resource about rights and opportunities;
- give support as the learners make changes, accepting mistakes and inappropriate behaviour as part of the learning process.

It is the responsibility of the professional to work with whatever degree of communication — verbal or behavioural — the individual with disabilities can manage. In these terms, self-advocacy is contiguous with other forms of advocacy, as Wolfensberger noted:

A severely limited person learns self-advocacy best within the demanding shelter, protection, love and friendship of a citizen advocacy relationship, because these processes are especially apt to bring the person towards growth and independence. (Quoted in Williams and Shoultz, 1982)

No-one is incapable of self-advocacy.

A working definition of portfolios

The working definition of self-advocacy emphasises affirming the learner, offering choices, decision-making and effecting change. The aspects of portfolio preparation already outlined lend themselves to these aims. Recall of the past validates the learner's experience and puts his or her concerns at the centre of the stage. It also allows the professional worker to establish a relationship in which the learner feels safe and entitled to speak. Identifying what has already been learnt is another way of valuing the learner and of raising the sense of self worth. It also offers the opportunity for the learner to take on some responsibility for her or his own learning process and to become more actively involved in deciding what else needs to be learnt.

Collecting and presenting evidence of learning is a complex task, and is, in itself, a substantial learning experience. It involves the learner in a variety of decisions and choices, not least of which is the decision about the purpose of the portfolio, who is to receive it and what should be included. At the outset of the project it was less clear how — or whether — assessment of the portfolio should be carried out and who should be involved. This matter, and questions about the final purpose of the different portfolios, will be discussed later. In brief, portfolio preparation offered:

- **a means of valuing the learner and raising self-esteem**
- **a student-centred curriculum**

- **a focus for choice and decision-making**
- **a process for setting goals**
- **a new learning experience**
- **a means to effecting change**

It was with these fundamental principles, and with this skeleton outline of the potential of portfolio work that the key workers embarked on their part of the research.

Introducing the key workers for the case-studies

It is now appropriate to introduce the key workers in the project, and to outline their specific working situations. Table 1 is offered as a starting place for readers as it will not be possible to describe in detail each of the 11 case-studies. It should help to identify key workers and learners as they reappear at later stages in the report. Each case-study is referred to by the initial letter of the key worker's (fictionalised) name: so the case-study involving Anne is case-study A, and so on. The chart is most certainly not intended as a summary of those portrayed, merely as a reference point and a beginning. For reasons of confidentiality all names have been changed and identifying details have been omitted or altered.

- Column 1 names the key workers, gives their job title at the start of the project, together with a brief description of their background, their place of employment and the agency who actually provides their salary.
- Column 2 introduces the learners, indicates the source and level of their disability and outlines their position at the start of the project, as far as lifestyle and employment are concerned.
- Column 3 gives the setting in which the work of the project took place, which is not necessarily the same as the key workers' main place of work, and a rough indication of the time spent on the project work.
- Column 4 indicates the major agency or institution which administers and/or funds the dominant setting in which the key workers function. Once again this is not necessarily the same body that employs the key worker.

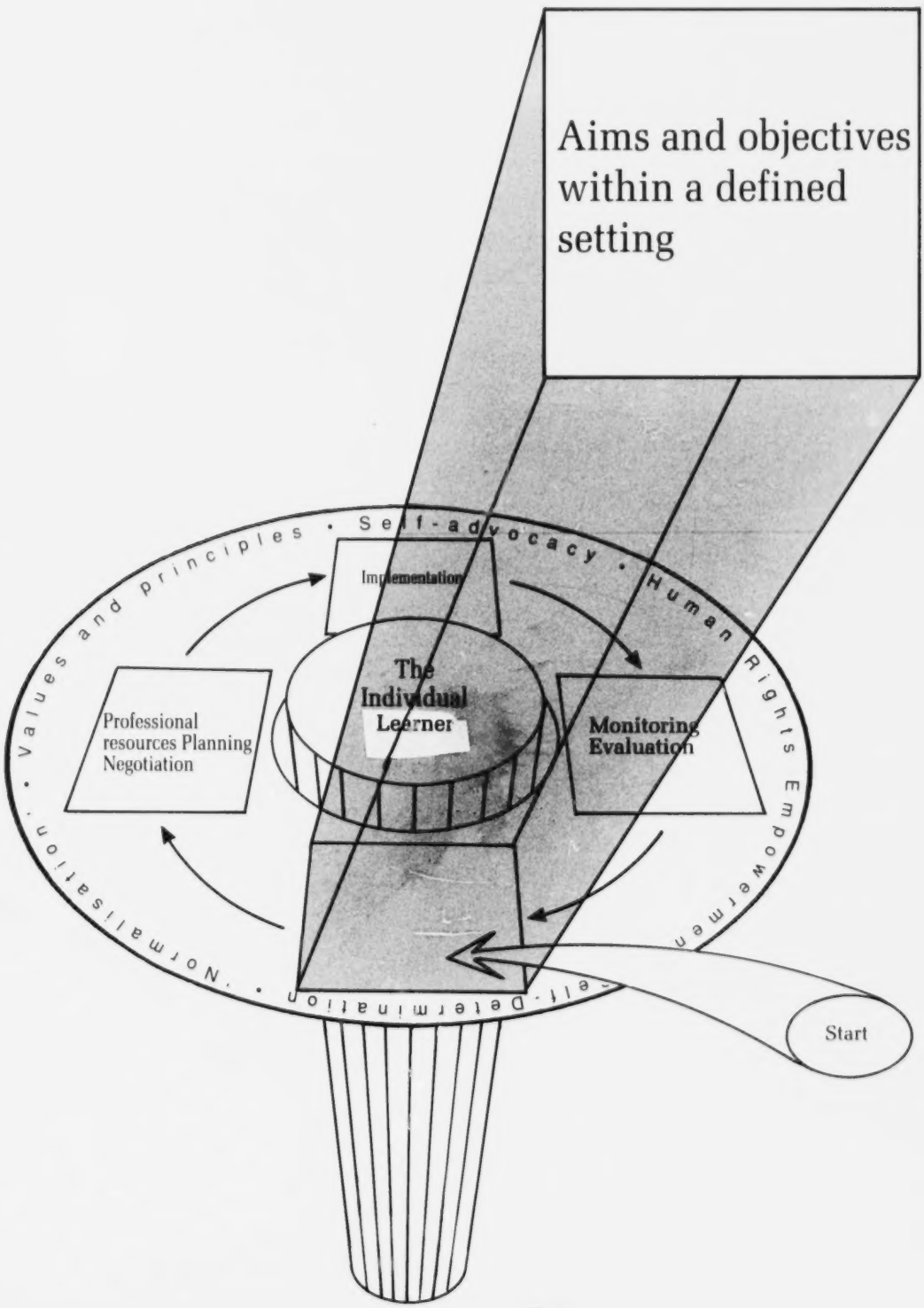
These arrangements are certainly complex. They are not easy even for professionals from disparate backgrounds to grasp. They suggest how difficult it is for people with disabilities to understand the network of provision, to identify who is responsible for what and to know how to get the information they need.

Table 2

Key-Worker(s)	Learner(s)	Institutional setting of project work	Agency Setting
A. Anne, mid-40s Educational therapist Background in FE special educational needs and work with unemployed adults. Employed by Hospital School. Founded by LEA. Cert. Ed. Dip. in Disadvantage; Dip. in Adult Education; B Ed. (OU); H Ed. (Interpersonal relations)	1. Jack, mid-20s, has a head injury leading to very specific cognitive/perceptual difficulties. He is an unemployed building trade worker. His parents have moved to live with him. 2. Patrick, 30s, had a traumatic head injury leading to motor and speech difficulties. He is an unemployed nurse, and lives with his girlfriend.	Rehabilitation Unit for people with Head Injuries One two-hour session a week	Health Service
B. Bruce, early 30s Support worker in community Background in commerce, psychiatric nursing and social science. Employed by social services project. Registered mental nurse. Dip. in Social Studies studying for P/t BA in Humanitites.	Harry, 50s, was a long-stay patient in a psychiatric hospital, but is now re-established in the community. He has additional physical health problems. He is unemployed, but was formerly a factory worker. He lives alone with support from his family.	Social service project for supporting long-stay patients returning to community. Up to five sessions a week, as needed	Care in the Community Joint Finance channelled through Social Services.
C. Chris, early 30s, FE lecturer in special educational needs. Background in primary school, special schools. Employed by LEA. Cert. Ed. OU Courses: Special Needs in Education Adult Education Handicapped in the Community	1. Alan, mid-40s, has been a resident in a hospital for 25 years. He has severe learning difficulties. He is entering preparation for living in sheltered accommodation. 2. Andrew, mid-20s, has been resident of a hospital for 14 years. He entered as a teenager into a unit for emotionally and behaviourally disturbed boys. He is of average intelligence but institutional life has led to some learning difficulties. He has worked as a postman within the hospital.	Continuing education centre located in mental handicap hospital One two-hour session a week and contact at other times	Health Authority
D. Debbie, early 30s, Special needs co-ordinator in FE college. Background in social services day care. Employed by LEA. B Sc Psycology, MSc Applied Psychology, C&G 731 CNAA Teaching Certificate'	A Group of nine adults, all of whom have severe learning difficulties arising from a variety of conditions. All except one attend day centres. Some live with parents and others in a range of residential settings. None in open employment.	Special Needs Department of FE College. One one-and-half-hour session a week	LEA

Key-Worker(s)	Learner(s)	Institutional setting of project work	Agency Setting
E. Elena, late 30s, area officer for a voluntary organisation supporting all people with moderate learning difficulties. Background in Health Service and local authority administration. Employed by voluntary organisation. Dip. in Social Sciences.	Val, early 30s, has moderate learning difficulties. She was a trainee and then community programme employee on a catering scheme run by the voluntary organisation. She lives with her parents and is seeking open employment.	Voluntary organisation One two-hour session a week	Inner Area Programme via County Council
F. Frankie, early 30s, FE lecturer in adult education employed by FE college but located four days a week in adult education centre in mental handicap hospital. Background in special education for children with severe learning difficulties. Employed by LEA. B Ed. for children with learning difficulties	Jonathan, mid-30s, has cerebral palsy leading to lack of speech, quadriplegia and severe learning difficulties. He also has some visual impairment. He has been a resident in hospital since childhood.	Adult Education Centre and wards of mental handicap hospital. One one-hour session a week and one two-hour session with a group plus time for liaison.	Health Authority
G. Gayle, late 20s, FE lecturer in special education needs. Employed by the LEA. Background in commerce and administration and earlier REPLAN special needs project. BA, PGCE, C & G 731.	1. Althea, early 20s, is of Afro-Caribbean origin, with a history of emotional difficulty. 2. Dawn, mid-20s, has moderate learning difficulties and loss of vision in one eye. She was taken into care in her teens and now lives alone with substantial support from social services. She is in the first year of a two-year course.	FE College One one-and-half-hour session a week	LEA
H. Harriet, mid-20s, Day Centre Officer. Background: health authority and social service provision for disabled adults. Social service resource centre for all disabled people up to 65 years, social services run. Open to any community groups who will incorporate centre members in their activities. Employed by social services.	Penny, mid-20s, has cerebral palsy leading to use of a wheelchair and limited motor control. She lives at home with parents, and attends a computer workshop which offers supported employment opportunities as well as the Resource Centre.	Resource Centre Up to three or four sessions a week for a variety of purposes	Social Services

Key-Worker(s)	Learner(s)	Institutional setting of project work	Agency Setting
I. 1. Ivor. FE lecturer with responsibility for hearing impaired students. Background in special education unit of FE college. Teacher-trained at NE college. B Ed: University Dip. for teaching deaf students 2. Isabel. Social work assistant in special S W Team for deaf people. Background - caseload based in community. BA Hons. Sociology.	Edward, early 20s, has profund and pre-lingual deafness leading to severe speech difficulties; he also has mild cerebral palsy leading to general difficulties with physical co-ordination. He lives at home with his parents, and is on placement at a horticultural unit for people with learning difficulties.	FE college One two-hour session a week + one visit to parents each three weeks + liaison with other agencies + Isabel's case-work with family	LEA
J. 1. Jane, late 40s, qualified social worker. Background in clerical work, play-groups, and Family Aid before social work. Community mental services. CQSW; C & G 730. 2. Jenny, mid-20s, occupational therapist. Background: work with elderly people and then with people with learning difficulties. Community mental handicap team. Employed by health authority. Dip. in Occupational Therapy.	People First group made up from attenders at local day centres. All have learning difficulties of varying severity. The group meets in a venue that belongs to an educational voluntary organisation. Members come from a variety of residential backgrounds. None have open employment.	Community Mental Handicap Team (Multi-disciplinary). One two-hour session per fortnight, later per week	Social Services and Health Authority
K. Kevin, mid-20s, head of FE unit for students too disabled to attend a mainstream college, especially those with a shortened life expectancy. Background: accountacy and youth work. Employed by LEA	Amrit, early 20s, has Duchenne's muscular dystrophy, leading to severe loss of motor function and use of a wheelchair. He lives at home with his parents who are South Asian. He is of very high academic ability, and in the first of a possible maximum of three years at the Unit	FE unit for profoundly disabled young people. One one-and-half-hour session a week plus contact on a daily basis.	LEA


Aims and objectives within a defined setting
Values and principles • Self-advocacy • Human Rights Empowerment • Normalisation • Self-Determination •
Implementation
The Individual Learner
Professional resources Planning Negotiation
Monitoring Evaluation
Start

31

Section 2. Aims and objectives

The relationship to vocational preparation

This stage of the project was about developing specific aims and objectives in the light of available resources (see table 1). The key workers had all been involved in developing and refining the definitions of self-advocacy described in the previous section. These form the encircling principles, and also help to identify overall aims. The key workers also had the concept of portfolio preparation to guide them in the identification of objectives. In many ways these aims and objectives have much in common with the generic framework for vocational preparation defined in *Relevance, Flexibility and Competence* (FEU, 1987).

Some of the principles of self-advocacy are on a continuum with mainstream practices in non-advanced further education, although there may be differences in several important respects. Firstly, the learners involved may be much less advanced along the path to adult status. Secondly, self-advocacy is concerned to ensure that learners are themselves able to identify what is of relevance to them and that they are not prematurely excluded from attainable goals by the inadvertent power of institutional or professional assumptions. Thirdly, many learners with special needs have depressed expectations, and professionals need to draw out the lessons to be learned from the disability itself and not overwhelm the learner with expert theory.

Professional and human resources

When they came to consider the question of resources, several of the key workers expressed reservations. They identified themselves and their professional skills as key resources, but felt there were a number of important issues to consider before embarking on the work. Although they were volunteers who felt a particular interest in exploring this field, some of the group expressed doubts about their professional role in developing self-advocacy skills with disabled learners. These reservations were well grounded and covered a range of issues which need to be carefully

considered before embarking on this style of work, especially as some of them may affect the definition of objectives. This section will look at some issues that need to be resolved, or at the very least considered, before beginning any self-advocacy initiatives.

The paradox of professionals and self-advocacy

There is an undeniable paradox in professionally led self-advocacy work. Whatever the degree of personal sympathy with, and commitment to, disabled people felt by the professional workers, they are still in a position of power; it is their descriptions, assessments and evaluations, as well as their knowledge of available opportunities, that will often be effective in determining the course of a disabled person's life. Their professional identity, and certainly their professional accreditation, will be based on their control of knowledge about disability. To winnow out what is useful from this, and then to find ways of sharing it, is not an easy task. It sometimes seemed to the key workers that their power was almost wholly negative, always coercive or restrictive. They were keenly aware of asymmetries of power in their relationship with the learners. The only answer to this conundrum is the realisation that power can also be productive and creative; by redeploying their power, professionals are well placed to be good allies to disabled people. However, it was this discomforting awareness that continuously led the key workers to question what they were doing in ways that were to prove very productive. Initially, however, they identified a number of problem areas in undertaking this work, concerning their own capacity for it. The following sections deal with the relevant issues. The case-study details referred to can be found in Appendix D. **It is strongly recommended that individuals or teams of workers who wish to involve themselves in self-advocacy work, give serious consideration to this section of the report and raise the issues described in it within their own organisations and with senior managers.**

Dealing with emotional distress

Several key workers felt that openly considering the past, present and future might prove distressing for some of the learners. The past was seen as a particularly difficult area for individuals with a history of institutionalisation or absent opportunities, as well as for people recently disabled by traumatic injury. The future is particularly uncertain for this last group of people, as it is for individuals with progressive diseases. It seemed likely, therefore, that learners with these sorts of experience would have a great deal of distress that had never been expressed. Both self-advocacy and portfolio preparation are, at some stage, likely to confront

learners with painful feelings and experiences that they may previously have dealt with either by burying or denying them.

Professionals need to ask themselves a set of questions about these issues:

- **Do I have the necessary skills to support people experiencing emotional distress?**
- **Does the learner have the inner resources to look at difficult personal areas, and to sustain this sort of work?**
- **Do I have the experience, knowledge and skills to make such judgements about learners?**
- **Can I identify other forms of external support so that whatever happens the learner will be taken care of?**
- **Do I have the necessary professional support and supervision to allow me to undertake this work as rigorously as I would any other professional activity?** (See case-studies A and K)

Choice and consent

The key workers were aware that, because of their professional role, they were in a position to decide whether or not the learners with whom they worked should become involved with self-advocacy and portfolio work. They also found it hard to explain to the learners what participation in the project would mean. Neither self-advocacy nor portfolio preparation are easy concepts to convey in the abstract, especially to people with learning difficulties. Since the consequences and outcomes of the work were also unknown and somewhat unpredictable, it was hard to see how learners could freely agree to take part. This all raised some acute questions that are pertinent for all professionals considering developing self-advocacy and portfolio skills:

- **What are the grounds for my decision to try to introduce self-advocacy and portfolio work?**
- **Have I shared the processes involved in my decision-making with other professionals?**
- **To whom do I consider myself accountable?**
- **How can I try to involve learners in the decision?**
- **Have I considered how to gain meaningful consent from the learners?**
- **Am I prepared to reconsider my decision in the light of the learners' future reactions?** (See case-studies B and F)

Raising learners' expectations

Not all key workers were well placed to become involved in life changes for the learners they were working with. This was especially true of those lecturers in FE colleges who were dealing with learners in groups rather than on an individual basis. Although they might be successful in raising the expectations and self-esteem of the learners, as professionals they had little control over the material resources needed to fulfil new goals and aspirations. They were also very aware of the suggestibility of these learners, especially those with severe learning difficulties. Again this brought into high relief questions with wider significance:

- **Is it appropriate to timetable self-advocacy skills for just one-and-a-half hours a week?**
- **Do the rest of the learning opportunities I offer have the principles of self-advocacy at their centre?**
- **Are there any real choices available for the learners to make?**
- **Will encouraging self-advocacy only lead to disappointment, confusion and conflict, which it is no part of my brief to deal with?**
- **If people seem happy enough as they are, is it right to try to encourage higher expectations and to increase discontent?** (See case-study D)

Conflict with colleagues

As the table of case-studies indicates, several of the key workers were employed in multidisciplinary settings. In such institutions or agencies there may well be no consensus over principles across the different professions. Within hospitals, a specialised unit, such as a continuing education centre or a rehabilitation unit, might have its own goals of promoting independence and personal effectiveness with disabled people; these aims, however, may be at odds with the dominant medical ethos.

Medical ethics have long forbidden taking risks with patients and have strict protocols for introducing untried methods of treatment or care. The difficulty is that these attitudes have developed from work with sick or injured people, whose needs are different from those of people with disabilities. In addition, the medical model of care individualises problems. It sees the source of the problem as being the handicapping condition 'in' the disabled person. This ignores the complex ways in which society limits and ignores people with disabilities so that their original difficulties are magnified and multiplied. This is particularly true of people who have become passive and helpless in order to adapt to the demands of institutional living based on hierarchies and on the differences between the 'normal' staff and the 'abnormal' residents.

Such differences of perspective between professionals led to self-questioning for more than one key worker:

- **Am I right to encourage learners to go in new directions and to boost their self-esteem, when this makes them vulnerable to being knocked back by adverse criticism and, sometimes, hostility to their efforts?**
- **How should I deal with other professionals who fail to see learners' achievements and focus only on their inadequacies?**
- **Whose responsibility is it to ensure that learners' mistakes are seen as grounds for further work and not an indication that they are permanently unable to achieve?**
- **Is it possible to promote self-advocacy except in an environment that is wholly oriented to that end?** (See case-studies C and J)

Taking on an advocate's role

While all key workers shared these concerns to a greater or lesser extent, some had other concerns as well. In deciding to develop self-advocacy skills with someone with profound limits on communication, a professional worker may feel him or herself already privileged in his or her knowledge and understanding of that person's rights and wishes. Some hard questions can then arise, even at the prospect of beginning such work:

- **Can work of this nature be separated from the moral responsibility of taking on the advocate's role?**
- **How and by whom can the learner's interests best be represented?**
- **Is it appropriate for me to share confidential, institutional information with parents or other allies, so that the learners' voices, or those of their supporters, can be heard when plans for their future are made?** (See case-study F)

Imposing standards

Many learners are highly susceptible to suggestions, especially from those they see as having authority over them, and this is often compounded by the restrictions placed on their experience. These factors provoked concern, particularly from the key workers engaged in rehabilitative work, or in work that involved the learners in establishing new life-styles. Such questions came to have a wider resonance in the course of the project:

- **How can I avoid imposing my values or tastes on learners who are vulnerable by reason of their dependence on me, or by the conformity to authority produced by being in an institution?**

- **How can I, as a white, middle-class professional, respect decisions and life-styles based on working-class or black values and tastes that arise from a different social perspective?** (See case-studies B and G)

Working with parents

At the beginning of the project the key workers anticipated that conflicts of interest would arise between the disabled adults and their parents, and also, potentially, between the parents and themselves. The prospect of conflict often causes people to identify strongly with one point of view and to become entrenched in their defence of that position. This potential was present when the key workers asked themselves:

- **Whose side am I on? Where do my primary loyalties lie?**

However, if there is a learner's right to self-advocacy, there must also be a right of parents and carers to self-advocacy on their own behalf. The key workers, therefore, also quite rapidly came to ask:

- **Who is supporting parents in their right to speak for themselves?**
- **Why do parents react in these ways?**
- **Is developing self-advocacy skills with disabled adults necessarily going to imply working with their parents, carers and other closely concerned people?**
- **Can I, as a professional working with the empowerment of disabled adults, afford not to see the parents' point of view?** (See case-studies E, K and I)

Many professionals working with disabled people of all ages are thinking about how to promote transition to adulthood with and for people who have previously been denied the opportunity, and how best to foster their autonomy and independence. Developing self-advocacy skills is one aspect of this process. Inevitably this leads to the involvement of parents and a consideration of the role they play. This is a potentially difficult and sensitive area where the concerned professional needs to bear in mind a number of important issues; some are outlined below.

Alison Wertheimer's work (1989) has indicated a clear gap between the attitudes of parents and professionals to the issues of independence and autonomy for the disabled people in their care. Parents' views will have been shaped by many years experience of professional support, which they may well have found unreliable, inadequate or insensitive. They will be aware that society does not welcome disabled people and is only reluctantly adapting itself to their needs. It is, therefore, not surprising that parents of disabled people should be sceptical of the potential for change. This may be especially true when this represents a shift in the line of professional opinion that was current in their child's early years. At this

stage, parents were adapting to the reality of having a 'handicapped' child and, 'it is doubtful whether a mother can care for even a year-old child without taking into account his present and future social identity' (Roskies, 1972). Parents are therefore being asked to undertake a major redefinition, both of their child's identity and their own role in their family and in society.

It is clear that 'letting go' of growing children is an ambiguous experience for **all** parents, and that ambivalence is common. However, with growing physical independence and increasing social support from their peers, most non-disabled young people can provide the necessary impetus to separate from their parents. Without this push from the adolescent child, it is very hard for parents of young disabled adults to undertake this stage of disengagement without feeling that they are also rejecting the disabled person. As adolescence is lengthened or indefinitely delayed, the family may settle itself into a pattern of emotional interactions which take for granted the absent adulthood of the now fully grown child, and which are centred on the disabled person's continuing dependency on the parents.

There are other practical elements outside these family relationships that may make parents uncertain about how realistic a more independent life-style is for their child. These include the fear that others cannot give the quality of physical care needed that they as parents provide. Parents may have vivid knowledge of the struggles involved in obtaining benefits and other social entitlements, and they may also recognise the painful reality of the social stigma attached to being handicapped. They may have very real reasons for believing that disabled people are especially vulnerable and need special protection. None of these considerations — emotional or practical — can be lightly dismissed. Unfortunately, realising the need for this essential co-operation with parents to be established does not answer the crucial question:

- **Who has the recognised responsibility for supporting parents through this difficult transition and for meeting their legitimate doubts?**

Professional responsibilities

In these difficult and uncertain areas, it became clear that certain aspects of professional practice were even more important than usual. Since the key workers were both objects and subjects of a research process, rigorous **record keeping** was built in as an aspect of their experience. Although it seemed daunting and an additional and rather burdensome task, all of them acknowledged its value in developing personal and professional learning. Without careful records and the thinking that has to go into keeping them, there can be no:

— assessment of progress

— development of strategies

— identification of important issues

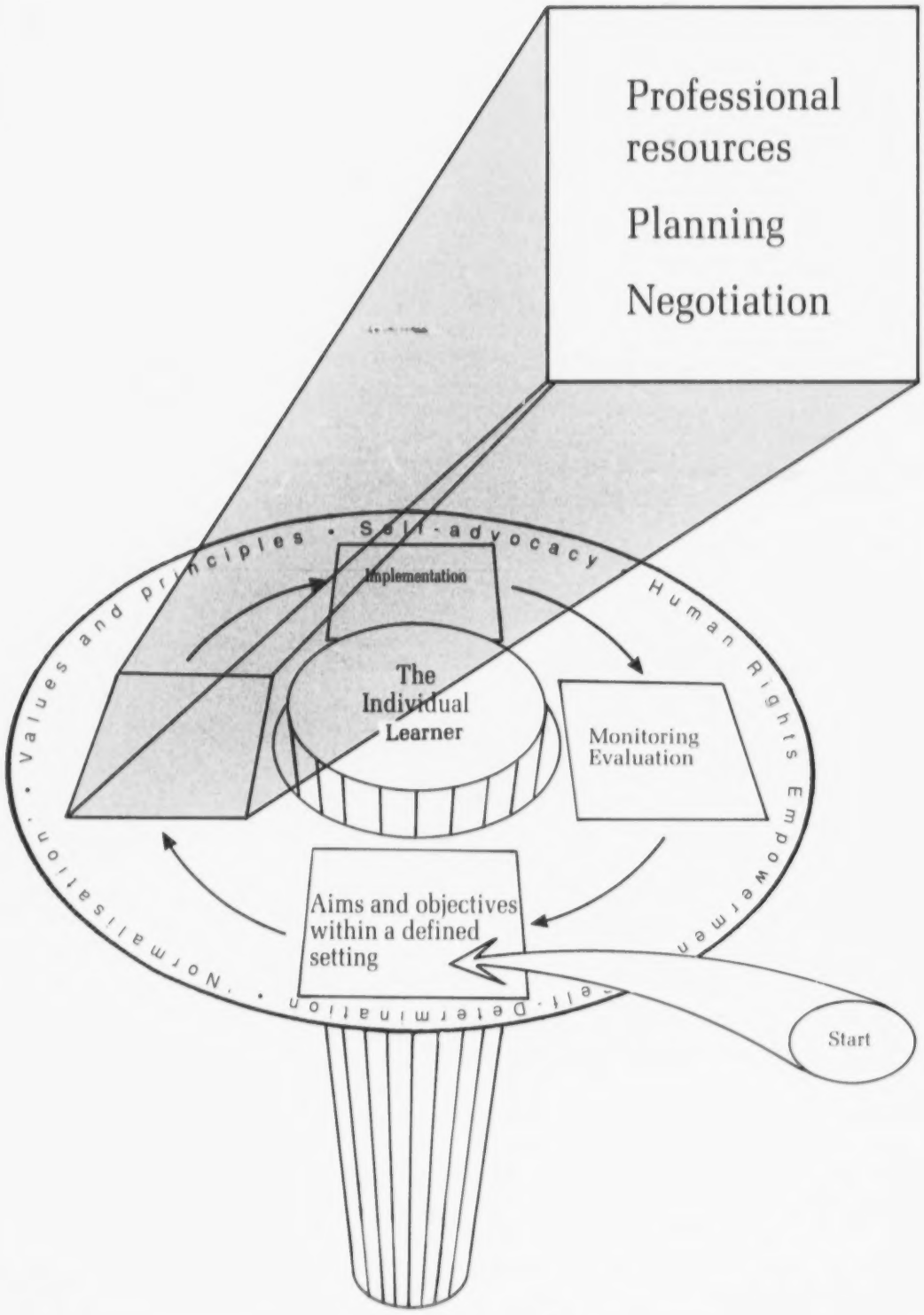
— analysis of success and failure

— negotiated goal setting

— clear evidence of outcomes

There were also questions raised about who should keep the records. As far as the research process was concerned, at least two of the learners decided that they definitely wanted to exercise the right to see and, if necessary, to veto any material about themselves. These decisions helped the key workers to appreciate that one of the values of keeping open records is that it obliges the professional to make a clear separation between agreed or factual statements about the learner, and comments that in reality are expressions of the worker's own feelings or frustrations. So the initial questions that arose were:

- **How can I maintain confidentiality?**
- **How can I involve the learner in the keeping of records?**
- **Exactly what do I need to record?**
- **What is the best, most sustainable method for me of keeping records?**
- **With whom am I going to share these records for reasons of professional supervision and support?**
- **What is my purpose of recording material that I would not be prepared to share with the learners, and how do I justify it?**


Professional resources
Planning
Negotiation
Implementation
The Individual Learner
Monitoring Evaluation
Aims and objectives within a defined setting
Start
Values and principles • Self-advocacy
Human Rights Empowerment
Self-Determination • Normalisation

Section 3. Planning and resources

Self-advocacy and portfolio preparation

Aims and objectives

Within the context of this project, portfolio preparation was subsumed into the overall aim of developing self-advocacy skills. A general definition of these has already been given. However, establishing the specific objectives for developing self-advocacy skills with a particular learner or group can only be done over time. The learners are at the centre of the curriculum process, and both their goals and appropriate methods of learning have to be negotiated. As Kevin wrote at the beginning of the project, 'the self-advocacy must be free-flowing and allowed to develop as the student leads or directs'. There can, therefore, be no blueprint for introducing portfolio preparation into this process.

Tasks and processes

Instead of writing a plan of work that includes clearly defined content, the professional needs to follow a **sequence of tasks and processes**, and, in these initial stages, to tolerate a high degree of uncertainty. This is far from being an abnegation of responsibility; on the contrary, it requires of the professional a new and more demanding way of working. In some respects none of this is new, although the process is in sharp contrast to designing courses around an examination syllabus. In adult basic education and in outreach work with unemployed adults and disadvantaged groups, such an approach is already common. The processes and skills described here are particularly relevant to meet the growing demand for the accreditation of prior experiential learning; as NVQs become a more flexible and open route to vocational qualifications, and as FE devises the more responsive and modularised forms of learning and institutional organisation that individualised programmes will require. These changes in approach and organisation will involve educators in developing an even wider professional repertoire. The interpersonal skills of negotiation, counselling

and guiding will need to be added to a sound knowledge of a particular vocational or academic area. (CBI Doc)

In this context the tasks of the key workers were to be found underthe following headings.

Possible objectives for portfolio preparation

Although this cannot be an exhaustive list, possible uses identified within the project included:

- raising the learners' self-esteem
- helping the learners to define and represent themselves within a supportive context
- identifying and recording knowledge and skills
- communicating with other people, in both formal and informal situations
- as a focus for developing skills of decision-making, goal-setting, self-assertiveness, and self-presentation.
- as part of a job search programme
- as a means of gathering and recording information
- as a personal journal, allowing for reflection and self-analysis

Identifying limitations and resources

Closely linked to the theoretically possible uses and purposes of portfolio work, were practical questions about what could be undertaken realistically. This involved looking at:

- professional roles in terms of:
  - available time
  - degree of involvement in initiating and supporting material change in the learners' lives, e.g. employment
  - group or individual work
  - the availability of support and supervision
- the position of the learners in terms of:
  - their ability to produce material independently of the key workers

- their existing confidence in being able to define their own goals
- the presence or absence of current opportunities for change in the learners' lives

Negotiating with the learners

The key workers' first tasks were to introduce the individuals with whom they were working to both self-advocacy and portfolio preparation as well as seeking their consent to be part of a research project. (For exceptions see case-studies J and A.) It became apparent immediately that real consent implies having clear information and relevant experience. In most of the case-studies the learners had had little of either. Introducing new ideas and making agreements, therefore, could not be understood as activities to be accomplished in one or two sessions; they are both ongoing processes which may take months. So the problem that faced the key workers was how to begin. One key goal was to put the relevant issues and information on the learners' agenda. Of equal importance was the necessity to win the learners' trust and to make them feel valued and respected. Simple strategies proved most effective. These included:

- agenda setting:
  - beginning to use the terms 'self-advocacy' and 'portfolios' and to explain their meanings
  - asking a visiting speaker to present the ideas
  - attending a self-advocacy function such as a People First conference
  - discussion and sharing of professional materials with the learners
- practical steps:
  - arranging for the learners to choose and purchase a special folder or book for their portfolios
  - agreeing on a special time and place to meet
  - using concrete ways to help the learners begin to present themselves and their experiences. This could be through old photographs, taking new ones, using video or sound recording, making pictures, autobiographical writing, playing games involving choosing, expressing wishes, and other exercises in self-development
- style and approach:
  - inviting the learner to make choices
  - working with the learners' responses

— expressing interest in the learners' goals for the future

— making an agreement about confidentiality

Process and product

Where clear aims were defined by the learners, portfolio preparation was introduced as a means to achieving them. Where employment was an established goal, for example, the use of a portfolio as a finished product can easily be seen as a means of approaching a prospective employer. (See case-studies E and I.) Portfolios were also introduced into an existing self-assertiveness course. (See case-study D.) In other instances, what was learnt during the processes of making a portfolio was as important as the finished product. In fact, portfolios can be thought of from two quite different perspectives: either as process or as a product. These are the opposite ends of a spectrum of possibilities, described in Table 3. In reality, the two extremes combine and merge in an infinite number of ways, but it is helpful to recognise these two tendencies.

Table 3

Goal orientated	Self-orientated
Structured by already defined external goals and made for a practical purpose.	Structured by a sense of inner identity extending through past, present and future.
Self-analysis may reveal aspects aleady extant within the learner which fit the defined goals	Aspects of the self explored for their own sake, including areas considered confidential or personal to the learner.
Includes evidence of skills, knowledge, etc. judged to be appropriate in achieving goals	Emphasis on life experience with focus on what has been learnt from it without any pre-conceptions about relevance
Designed to be read by others	Concerned with self-exploration and self-definition
Entries all produced with certain goals in mind	Holistic. Concentration on the subject may in itself arouse a response to be valued so there should be no limits on where the process might lead, i.e. emotional or psychological areas are just as valid. The process as a whole may legitimately supercede other outcomes.
Edited for a particular purpose	All inclusive. Might contain material useful for influencing other people, or evidence of competences and knowledge, but as a by-product.

Part of the early negotiations with learners will centre on the sort of portfolio that they wish to produce and their ideas for its possible use.

Public and private

These contrasting styles of portfolio work point up a commonly accepted division between what is considered as 'private' and what is seen as being 'public'. In the lives of disabled people these distinctions often become blurred. Adults gain the control over their own lives and identities that allows them to demarcate some areas as private; lack of adult status for disabled people denies them control over their own privacy, access to the public world of work and active citizenship, and the richness of a sense of themselves as being able to enjoy a diversity of roles. It is also one of the markers of adulthood that people are able to regulate access to aspects of themselves that they do not wish to share. For disabled adults, a feature of social interactions is that others feel free to approach and question them in ways that are not normally acceptable between adults. Professionals therefore need to ensure that they do not breach an already fragile sense of privacy. The issues of what aspects of the self to reveal in what situations may need to be dealt with very directly. Professionals working with portfolio preparation therefore need to ask themselves continuously:

- What must I do to ensure that the learners understand that they are entitled to privacy and can choose to withhold information?

Taking care

Trust and safety

It must be emphasised that, like self-advocacy work, the success of portfolio preparation depends on the attitudes of the staff. To be effective, portfolio work requires the learners to look in depth at themselves and their lives. This is not a possible or a productive undertaking if individual learners feel threatened, judged or in any danger of not being taken seriously. It is not just a question of how the learners feel; the staff working with them need to prove themselves to be trustworthy, loyal and supportive. This requires staff to maintain confidentiality, to avoid judgements that have no explanatory power, such as characterising individuals as 'manipulative' or 'attention seeking' and to try always to understand the grounds for any difficulties in competences or behaviour that the learners might have.

Dealing with anxiety

It is not only learners who feel vulnerable and anxious. As has already been suggested, self-advocacy and portfolio work are often, in the initial stages, an uncertain business, and anxiety amongst involved professionals is a natural reaction. The key workers faced the added pressure of being part of a research process which exposed them to greater scrutiny. It is

reasonable to suppose, however, that the research aspect only intensified worries that would normally occur in similar professional situations. Anxiety should be recognised as part of the process of this kind of work and not as indicating professional inadequacy or incompetence. Unless they are directly managed, latent anxieties are likely to re-emerge unexpectedly at a later stage and to sabotage what has been achieved. The key workers spoke at the outset about a range of anxieties, many of which were soundly based. A discussion of them forms the core of this section of the report. Behind them all, however, lurked the spectre of a worst-case scenario: a professional revealed, after a year's work, as totally incompetent, with no portfolios made and learners in exactly the same state as they were a year previously!

Effective management of anxiety can only happen within a supportive framework where it is acknowledged and analysed. Within the project this framework was provided for the key workers by the project officer, who in turn took her own anxieties to the project consultant and the project director. The key workers also provided each other with a network of peer group support, and several sought extra professional supervision elsewhere. Such support structures are essential for ensuring that professional workers feel confident and reassured about their own practice. This is not simply for their own benefit; unexamined anxieties are all too likely to be projected onto the learners, and this can have a variety of unfortunate consequences. The dangers are that insecure professionals may all too easily:

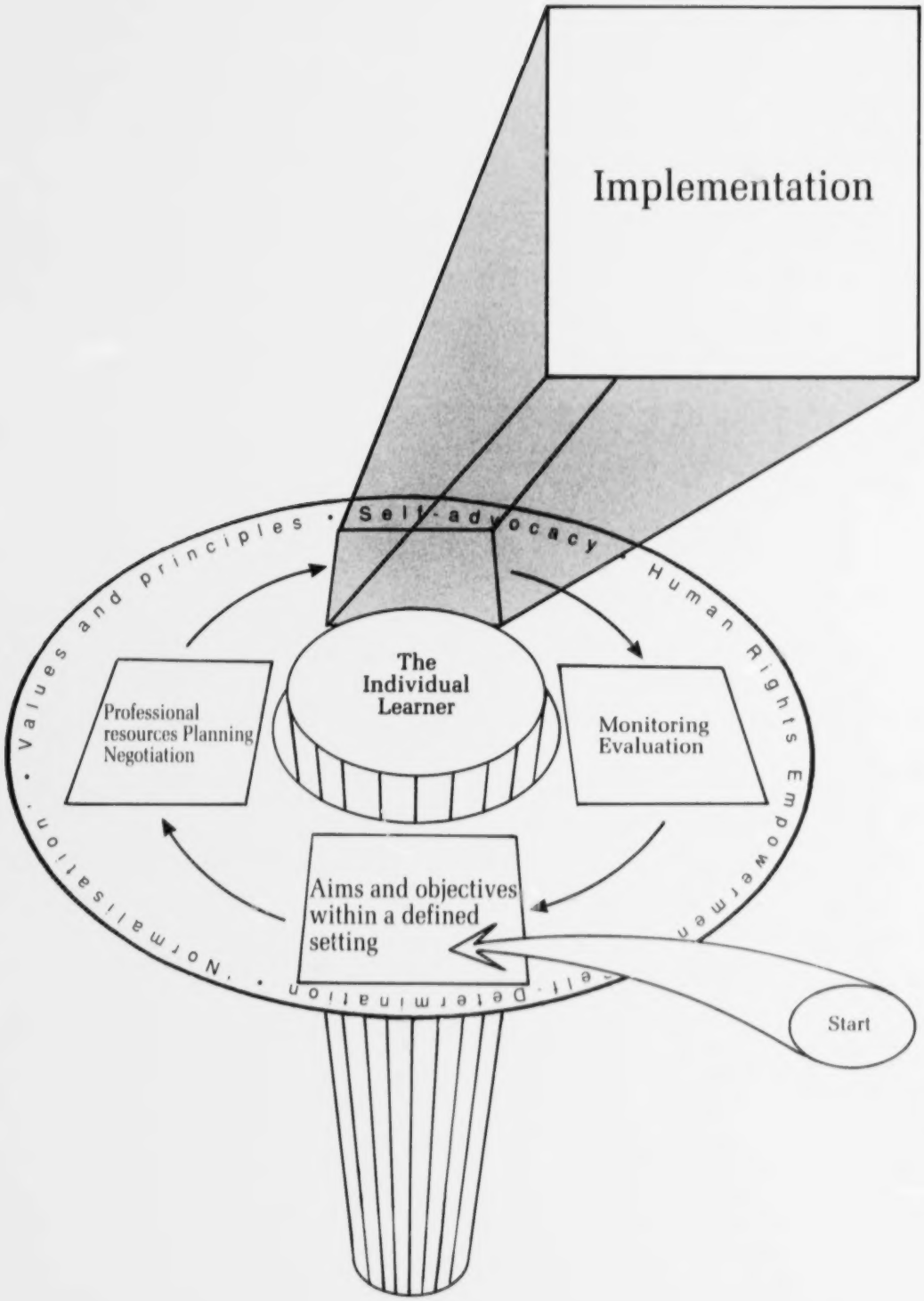
- short circuit the slow process of encouraging real self-advocacy and start to make decisions for the learners;
- put pressure on learners to produce concrete, visible results in terms of portfolio entries before the learners are ready;
- without the feedback of tangible results, feel that they have nothing of value to offer;
- conclude prematurely, through disappointment at the absence of dramatic changes, that the learners with whom they are working are incapable of self-advocacy or of portfolio work;
- fail to sustain an attitude of unconditional, positive regard.

These tendencies can be countered if there is supervision and support that:

- gives permission for such anxieties to be expressed without loss of face;
- emphasises the value of working with a long-term view of the processes involved in self-advocacy and portfolio preparation;
- recognises the worker's own skills;
- reinforces the worker's positive attitudes towards disabled people and their rights;

- upholds a view of the worker as a caring and competent individual with much to contribute;
- encourages self-reflection and consistently insists on relating practice back to fundamental principles.

Developing self-advocacy skills and portfolio preparation with disabled adults has clear implications for the management and support of professionals. People who do not themselves feel secure and valued are not likely to be able to value others. Professionals who are obliged to discount their own needs are equally unlikely to be able to act generously and creatively towards the learners for whom they have responsibility.


Implementation
Self-advocacy
Human Rights Empowerment
Normalisation
Self-determination
Values and principles
The Individual Learner
Professional resources Planning Negotiation
Monitoring Evaluation
Aims and objectives within a defined setting
Start

Section 4. Implementation

This section looks at how the key workers implemented the approaches outlined in the previous sections. This is stage 3 in the model offered in Table 1. However, before these specific experiences are described and analysed, there are a number of significant issues to consider.

Paradoxes of reporting self-advocacy

Whose knowledge?

Since the research was concerned with the whole notion of self-advocacy, there are numerous problems about representing experiences and the conclusions drawn from them. No knowledge or reporting can ever be neutral; it is always, inescapably, produced from a particular point of view, for a particular purpose and often within particular sorts of institutional frameworks. This report is no exception. Disabled people are wise when they insist on the right to represent and speak for themselves. There is every likelihood that, without direct experience of disability, the most sensitive professional will get it, ever so subtly, wrong. The descriptions that follow should be read critically, for, although they are offered in good faith and already have been scrutinised by the individuals represented in them, they can only partially represent the experiences of key workers and learners.

Fact or fiction?

Another factor that needs to be considered is the authorial role. There is no explicit account in the text of my experiences as project officer; my relationship with the participants, my problems and my solutions to them. Nor does it explain how I come to view the key workers, the learners, their parents and assorted other professionals . Yet all the data collected, and certainly its interpretation, is to some extent filtered through my consciousness. The relationships established with the key workers were probably quite significant in determining outcomes, and yet they remain tacit if not wholly unanalysed. Clearly the adoption of this authoritative authorial persona is common practice, and quite taken for granted, but it raises particular problems when dealing with self-advocacy. Authors of academic and professional texts strive for 'objectivity' by being abstract

and authoritative, and the text is amplified through publications, organisations, institutions, courses, conferences, in-service training and qualifications, and so becomes popularised and accepted as the truth. Their work seems to speak on behalf of a neutral and general knowledge. This, in turn, can distance professionals and make them relatively invulnerable to criticism from individuals whom they characterise. Disabled people often have only painful personal experience to set against professional expertise, and disclosing it may make them even more vulnerable. Anyone who is committed to self-advocacy for disabled people must consider all this.

What are 'attitudes'?

Although some attempt to avoid it has been made by focusing on the key workers, their experiences, their understandings and changes, there are far more personal details about learners than about the key workers. This may appear to be because it is the key workers' professional qualities that are the focus of interest, not their private lives; while, conversely, professionals who are trying to extend the adult roles open to disabled people have a legitimate interest in the whole of their lives, including accommodation, employment, mobility, domestic skills and even sexuality. Since this explanation is a partial truth it may sound plausible, but it does not altogether stand up to close examination.

Self-advocacy requires of professionals that they avoid making censorious or closed judgments about disabled people, and instead really listen to what these people have to say about how the world appears to them. This is an imperative towards a greater understanding, based on material that is not available to professionals from any other source. However, it is difficult to hear other people and to understand them, without having a clear and solidly based understanding of yourself. It seemed to the project officer that many factors quite outside their professional training and experience affected the commitment of the key workers to the principles of self-advocacy and also their ability to implement the work. These perceptions were confirmed in discussions with them. Experiences of exclusion, failure or stigma were all cited as valuable in leading the key workers to a commitment to self-advocacy, and as fundamental to shaping their attitudes. Sources for these experiences were:

- social origins: a working class or minority cultural background
- being a DHSS claimant
- involvement in campaigning
- Trades Union membership
- failing the 11+
- sexual harassment
- gender discrimination

The key workers were also generous in openly discussing current and past autobiographical experiences that they felt actively coloured their present work. These included key workers reflecting on the way relationships with their own mothers or lack of parental support in their own lives predisposed them to view the parents of learners in particular ways. It was also evident that key workers' own sense of self-esteem was essential if they were to be effective. For more than one key worker, a series of painful and disempowering events in their private lives left them temporarily feeling so devalued that they felt they had nothing to offer their learners. These feelings were particularly active in preventing them from 'selling' self-advocacy and portfolios to the learners.

All this is lost in the accounts offered here. Certainly it would be confusing and laborious to include them, but their omission suggests that professionals operate in a social vacuum, unaffected by their own position, and past and present experience. Their absence also suggests that 'attitude' is something that can be easily developed or changed. The evidence from this project would be that this is not so, and that it will only be accomplished by a certain amount of self-examination closely coupled to an analysis of power relations.

In writing up the case-studies, truncation was inevitable through lack of space. What appears here is perhaps 15% of what is available. The accounts try, nevertheless, to be just, and to see the point of view of everyone concerned. They also seek explanations and try to illuminate the grounds for the choices made by all the participants. They try not to ascribe blame to anyone. Inevitably, however, some situations are delineated where those involved acted without recognising the impact of the ramifications of their privilege and power on those less advantaged. Again, these considerations represent another set of reasons for wishing to present readers with a multilayered description, so that they may make judgements of their own.

Reading the case-studies

A further consideration in writing up the work of the project is that, although the principles, aims, and objectives were held in common by the key workers, their working circumstances differed widely. As a result, the scope and detail of what each of them actually did are not easily condensed into a general picture. The key workers recognised in each other's work the same issues and difficulties that they all faced, but what these actually meant in practice was bewilderingly diverse.

In undertaking the work, they encountered a variety of constraints and dilemmas, so the skills and strategies needed to overcome or resolve these will be examined, but the key workers were all agreed on the most important processes involved, and this section will be organised to look at each one in close-up. It has to be recognised that these processes can often only be separated one from the other with difficulty. To demonstrate this, a

brief incident from one case-study is given here with indications of the variety of issues that might be drawn out from it. This is also the case with each of the more substantial accounts which make up the core of the following section, although each one is intended to exemplify one particular issue. Readers can gain an important understanding of the nature of this work if they consider for themselves what other issues are demonstrated in these fragments, and how the different areas interrelate.

Adult roles

As adviser to the student's committee she accompanied Stuart to a meeting of the Academic Council at which he was to deliver chairperson's report for the Students' Council. She had previously helped Stuart to write the report and corrected his spelling. He had then asked the secretary to type it for him as it was to be distributed to the Council members. The meeting was formally conducted in an imposing room. Chris rehearsed with Stuart the reading of the report, and role-played with him some questions that she thought Council members might ask, especially as she judged that self-advocacy was unknown territory to many of them. She therefore focused on the County self-advocacy meetings which Stuart had attended and the fact that the hospital group had recently affiliated to the NUS and received £260 funding from the County Council.

Self-assertiveness

Learning from mistakes

Stuart was understandably extremely anxious at the meeting but listened quietly, while Chris sat next to him and showed him where the meeting was on the agenda. When he came to read, he was so anxious that he missed out words so that the report did not quite make sense . However all the members had the typed copy in front of them. Chris noted the questions that he was then asked. 'So you've been to a disco?' 'Was it good?' 'Was it noisy?' It was left to one of her close colleagues to take up the substantive issues of the report: 'Stuart, you have joined the union. What does this mean to you?'

Professional differences

Affirmation ——— After the meeting Stuart wanted to know if he had done well, and Chris realised that he had taken his report and the meeting very seriously; he had also understood the implications of his being there.

Learning from mistakes ———

Managing change

Self-advocacy is about creating change, involving processes and relationships that are difficult to pin down. There are other forms of post-16 education that share these characteristics. Shifts in pre-vocational education and training have already been noted, and to these might be added the experience of, for example, running writers' workshops in adult basic education, or tutoring women's courses in the style of Wider Opportunities for Women. In these situations educational experiences are often the trigger for wide-reaching changes in the learners' lives. There has to be a real sense that what happens is not wholly under the control of the professional worker; empowering the learner implies tolerating uncertainty, shifting professional roles and surrendering some professional power.

This is not a suggestion that anything goes; positive change implies development that stems from a clear sense of direction. It is unlikely to arise from situations where people feel unsafe; insecure professionals cannot create a safe environment for the learners. Foremost among the necessities for professional practice in managing change are careful record keeping and the non-judgemental professional supervision already described.

The experiential learning cycle, described in full in Table 4 and already outlined in Table 1, was used by the key workers as part of their record-keeping. It functions as a very useful tool in helping professionals to keep a grasp on what they are doing and where they are in the process, when the situation in which they are involved feels slippery and out of control. It also acts as a reminder that there are no final stages, no absolute outcomes, and that each point in the cycle leads on to the next. Best of all perhaps, it emphasises that professionals should constantly maintain a sense of themselves as learners too.

Making links

The key workers did not see themselves as developing self-advocacy skills in isolation from other initiatives and knowledge in the area. For most of them there was an active involvement with the self-advocacy and disability movements, and much use was made of existing materials. Some of the links made between their own work for the project and other activities and resources are outlined below:

- Ivor and Isabel enlisted, and paid for, the services of a respected member of the deaf community to work with Edward. The six-session programme included information about driving skills and personal education, with the overall aims being to improve Edward's use of British Sign Language, to introduce him to deaf culture, and to improve his self-esteem as a deaf person.
- Debbie and Elena both made use of the video *We Can Change the Future*, and both had previously accompanied learners to self-advocacy training events.
- The People First group with which Jane and Jenny worked was, of course, involved in the wider self-advocacy movement.
- Frances was involved in the organisation of day conferences for learners which aimed to promote the idea of self-advocacy among people with learning difficulties from outside the hospital setting in which she worked, and Gayle and Dawn were able to attend one such event.
- Chris was involved in several four-day training events for professionals run by the Continuing Education Centre where she worked. These were inter-agency occasions which explored the issues around the principles of normalisation and self-advocacy.

These connections added depth and further perspectives to their understanding of the work.

The following excerpts from the 11 case-studies are framed by all the considerations outlined above, but their chief focus is on exactly what happened between the professionals and the self-advocates, and on the circumstances that surrounded them.

Working with other professionals

Supporting a learner in self-advocacy often involves the professional concerned in a network of relationships with other professionals who may have considerable power and influence in the learner's life. This section looks at how complex these processes are in reality, and at the skills and attitudes needed to keep the goals of self-advocacy firmly in view.

Case-study C. Chris and Stuart

Situation

Chris understood that Stuart had been deeply affected by his life in the hospital, where he has been for 13 of his 26 years. He lived on a ward which had a 'disciplined' regime. This meant that Stuart had to ask the staff for any money he needed, could not make himself a hot drink or a snack, had no privacy, and could not choose what clothes to wear since they were kept locked up. For many years he had not had the opportunities for the normal experiences of boy- and manhood. Most of the residents were considerably older than him and so he had little contact with his own age group. There was an absence of the sustained affection and support commonly experienced within families, even where conflict and difficulty exists. He continued his obsessive hobby of collecting random bits and pieces which he then used to elicit responses from staff. A contract was made with him to encourage him to collect more constructive and useful items and to carry only very small things with him, but this strategy involved ward staff in the expenditure of time, money and attention, all of which were in short supply, so monitoring the strategy lapsed. Stuart can both read and write at a functional level, and had for some years acted as an internal postman within the hospital. He had also been elected chairperson of the students' committee at the continuing education centre which he attended.

Chris's strategies

Chris understood that Stuart's difficulties in learning and behaviour arose from his previous and current experiences that devalued him as a person. In order to counteract these she offered him alternative roles to that of 'resident'. Both as a student at the FE college and as chairperson of the students' committee, Stuart was able to make choices and develop skills. Chris's work with Stuart on portfolio preparation dovetailed with these important initiatives, but also allowed her to develop a consistent one-to-one relationship with him that came to be recognised as important by members of the hospital staff.

When the idea of a portfolio was introduced to him, Stuart understood it to be a 'life story' but could offer no suggestions as to any possible contents, nor could he see that any control over his future was possible. Chris accepted this as a starting point and throughout the portfolio sessions allowed plenty of time for Stuart to talk freely about himself. Initially it was very hard to elicit any information or contributions from him — 'like drawing teeth', she reported — and he needed many questions and prompts.

Nevertheless, the process helped him to accept that it was his life, his experiences and his skills that were the focus of the portfolio.

Over six months his portfolio entries included a developing range of topics, which featured pieces on:

- his different roles — resident, student, son, etc.
- his memories of his past
- his range of skills
- the college sessions he attends, his preferences and ideas for future courses
- evidence of his work as chairperson on the students' committee
- ideas for future living arrangements
- the value he places on going to church
- an identification of skills generally needed for living in the community
- a self-assessment of the skills he lacks or needs to improve based on HANC

In the first month Chris was recording the degree of Stuart's dependency on the hospital hierarchy. 'When planning an activity he always implies that he must seek the charge nurse's permission...and is [as] yet unaware that he can choose and make decisions, e.g. organise a tea dance without getting sanction from the charge nurse.' And in month three: 'Stuart has a fairly low opinion of himself, feeling he is useless and unable to do very much. He said that he had no talent and could not think of any skills that he had.'

Nevertheless he was beginning to make suggestions as to the contents for his portfolio and by month five: 'It is clear to see his happiness and pleasure when he has completed a piece of work for it. He gets quite excited. He fully understands the uses it can have. He volunteered that it could be used at an IPP meeting and he wants the psychiatrist to see it.'

A month later, Stuart himself said: 'I can do a lot; some people think I don't know anything.' In month seven he had transferred to a more enabling environment in the hospital and was able to make realistic assessments of his independence skills, ...responsibly admitting to the areas in which he had only some or little independence but quite rightly

stating that he had no opportunity to practise these skills through living in hospital, e.g. visiting hairdressers, making doctor's and dental appointments, budgeting....'

Dilemmas and resolutions

This process was not, however, a smooth progression during which Stuart drew a new sense of self-confidence from the respect and regard showed to him by Chris. It was a period marked by difficulty and conflict. Some of this arose because the range of activities which Chris undertook inevitably drew her into areas of Stuart's life beyond the Continuing Education Centre.

As adviser to the student's committee, she accompanied Stuart to a meeting of the Academic Council at which he was to deliver the chairperson's report for the Students' Council. She had previously helped Stuart to write the report and corrected his spelling. He had then asked the secretary to type it for him as it was to be distributed to the Council members. The meeting was formally conducted in an imposing room. Chris rehearsed with Stuart the reading of the report, and role-played with him some questions that she thought Council members might ask, especially as she considered that self-advocacy was unknown territory to many of them. She therefore focused on the County self-advocacy meetings which Stuart had attended and the fact that the hospital group had recently affiliated to the NUS and received £260 funding from the County Council.

Stuart was, understandably, extremely anxious at the meeting but listened quietly, while Chris sat next to him and showed him where the meeting was on the agenda. When he came to read he was so anxious that he missed out words so that the report did not quite make sense. However, all the members had the typed copy in front of them. Chris noted the questions that he was then asked. 'So you've been to a disco?' 'Was it good?' 'Was it noisy?' It was left to one of her close colleagues to take up the substantive issues of the report: 'Stuart, you have joined the union. What does this mean to you?'

After the meeting Stuart wanted to know if he had done well, and Chris realised that he had taken his report and the meeting very seriously; he had also understood the implications of his being there.

Chris gave Stuart a lift to his mother's house where he spends alternate weekends. She found that he took with him three suitcases containing his collection as well as an overnight bag. His mother, who is nearly 70, appeared very distressed when they arrived and rapidly told Chris that she felt she could not cope with Stuart's visits any more and certainly could not afford the £18 she paid for the taxi to transport him. Partly in order to handle what had unexpectedly become a very difficult situation, Chris pointed out to Stuart that if he left his collection behind he could use his bus pass to travel home. At this point Chris felt that Stuart's mother needed support, especially if she were to be enabled to view him as anything other than a naughty child, and that Stuart should be systematically encouraged

to take more responsibility for himself during these visits. However, she also knew that this was beyond her professional remit, and that there was no appropriate intervention that she could make directly, other than to discuss the issues with Stuart and to persuade him to change his behaviour.

When she returned to work after the weekend, Chris was asked for an urgent meeting with the charge nurse on Stuart's ward. Stuart's mother had telephoned the hospital to insist that he leave his extra luggage behind and travel on the bus. The charge nurse had then told Stuart that he was not to take any of his collection home with him next time on pain of the entire collection being thrown out. Stuart had argued back, saying among other things that he had rights. The charge nurse read this as disobedience and insubordination, and was seeking Chris's support as he knew the suggested change originated with her. Chris, however, felt that the months she had spent developing self-advocacy skills were now bearing fruit, even if not in a wholly acceptable manner. She also felt confident that by discussing the matter with Stuart, so that he understood his mother's point of view, he would have agreed to minimise what he carried home. Although expressing herself diplomatically she refused to break the trust and confidence she shared with Stuart.

In both this situation as well as in the Academic Council meeting, Chris was faced with situations where Stuart's abilities were not taken seriously and he was not treated with respect. Under these circumstances she felt it her job to continue to demonstrate that she valued him as a person and had faith in his capabilities. These were not the only occasions when she was asked to be involved in quite far-reaching decisions concerning Stuart.

In carrying out this work, Chris herself developed many skills, established clearly held attitudes and identified new tasks that would promote her professional development.

Skills

- Devising means of recording portfolio entries: check-lists, diagrams, flow-charts, dictation, using a camera, etc.
- Using a variety of techniques to stimulate Stuart into producing material: discussion, brainstorming, questioning, role-play, etc.
- Group work skills with the Students' Committee including games, quizzes, communication exercises.
- Interpersonal skills:
  - giving attention
  - non-judgemental questions
  - listening
  - giving positive feedback

— challenging

- Conflict resolution.
- Assertiveness.
- Maintaining confidentiality and trust.

Tasks

- Liaison with other professionals: attending case conferences and IPP meetings.
- Representing Stuart and supporting him in his own advocacy.
- Initiating the portfolio work.

Attitudes and personal qualities

- A clear commitment to Stuart's potential for change and development.
- Perseverance through the unrewarding period at the beginning.

Issues

There are significant grounds for misunderstanding between professionals of different backgrounds. Particular areas for concern are:

- confidentiality
- handling of inappropriate behaviour
- assessment of potential

Although concerned with practices, these differences frequently involve questions of principle and attitude. At present there is little structured support for professionals who wish to take part in inter-agency discussion that focuses on these matters.

Negotiation

Negotiation is often mentioned as an important tactic for professionals in providing student-centred learning. This case-study examines how it might be achieved.

Case-study A. Anne, Jack and Patrick

Situation

Patrick and Jack both attended a rehabilitation centre for head-injured patients where they received a variety of therapies.

Patrick was in his late 20s, had been severely injured and at the start of his involvement in the project still needed to use a wheelchair. His training had been as a psychiatric nurse, and he intensely disliked most aspects of being a patient. His girlfriend lived with him and provided all the day-to-day care that was necessary. Jack was a little younger, and had been left with fewer motor or physical impairments, but was struggling with a number of perceptual and memory difficulties. At the start of the project he could not recognise places or, sometimes, common objects such as a sugar bowl. He had also damaged the specific area of the brain that has the function of distinguishing faces, so he could not visually identify even members of his family. His parents had given up their own home to move in with him and to support him through this difficult time. For both learners it was too soon in the recovery process to know what were realistic expectations for future progress and improvement.

Strategy

In working with adults who have head injuries, Anne takes her cue entirely from the needs they express. Sometimes these may be immediate, as when an individual wants to know more about her or his medical condition, but lacks the confidence to ask the consultant. In these instances Anne will encourage them to write a list of questions they would like to have answered or will role-play the situation with them. As a last resort she will speak as an advocate for them. Jack and Patrick, however, found it less easy to define such specific goals. Under these circumstances Anne went through a painstaking process of building a relationship of trust with each of them. During the first three months, her work with Jack focused on his literacy needs and a gradual opening up of other areas, including talking about money, his girlfriend, his fear of death, and his depression that he used to be able to do so much more. During this period Anne consistently made suggestions, both practical and about learning strategies, which Jack was free either to adopt or to ignore. In month three Patrick joined the project, although still quite ill, and with very indistinct speech. It was difficult for him, in that condition, even to contemplate regaining some of his lost skills.

Dilemmas and resolutions

It was not until month four that Anne asked both of them if they would like to work together on portfolio preparation. In the first session she

suggested they look at the different roles they had each played as adults. She felt uncomfortable in persuading them to do this as it meant she was having to be much more directive than usual, although she had previously gained each learner's consent to being part of the project. Jack was immediately interested and pleased by the new ways of seeing himself. Patrick, however, described himself as a 'cripple in a wheelchair', said there was no point in what he was doing, and left. Anne found this whole experience quite distressing and feared that she had transgressed against the trust she had encouraged Patrick to place in her. To her relief, Patrick arrived early at the next session, obviously ready to try again. This was what Anne described as the 'watershed'. She had come prepared with check-lists to help the two learners identify the skills and competences associated with the adult roles they had previously talked about. Patrick was still resistant to talking about himself, and said quite directly that he did not like it. He found it particularly hard to own the qualities and competences that he still possessed, whereas Jack enjoyed the exercise and was pleased to see the substantial list of his own achievements. Nevertheless, despite these differences, from that point both learners took a keen interest in their portfolios. The contents came to include:

- photographs
- tributes from other people
- check-lists of skills and qualities
- reflections on their situation and hopes for the future
- poems (a request from Patrick)

The learners Anne works with attend on a voluntary basis. If they feel dissatisfied or under pressure, they can, as Patrick demonstrated, simply leave. Under these circumstances, negotiation of goals and the means to attain them are essentials for success. This works well when the learner has a clear purpose, such as recovering literacy skills, and understands the sort of processes involved in achieving such a goal. Difficulties arise, however, with the concept of portfolio preparation, when the thinking behind it is unfamiliar to the learners, or not understood or even straightforwardly rejected by them. Although over the following weeks Jack and Patrick arrived early and stayed late for sessions, brought in material, produced work at home and took their portfolios away with them, they still maintained that they did not really see the point in these processes. The main reason they agreed to become involved was because of the relationship of liking and trust that had been established between themselves and Anne. She experienced some anxiety in continuing with activities that did not arise explicitly from the expressed needs of the learners, although in retrospect it became clear that she was obviously meeting unexpressed or unacknowledged needs. This suggests that negotiation can be a long-term process which depends on trust as well as on the ability of the professional to provide for a variety of requests.

Skills

- Possessing a repertoire of teaching skills in:
  - adult basic education
  - self-assertiveness
  - language related skills
  - improving motor and perceptual difficulties
  - portfolio preparation
- Interpersonal skills.

Tasks

- Establishing relationships of trust.
- Offering a wide range of options.
- Acting as advocate.

Attitudes and qualities

- Tact and patience.
- Self-awareness about own reactions to disability and loss.
- Ability to tolerate stress.
- Confidence about the future possibilities for the learners.

Issues

- Real negotiation was possible in this case because the learners were able to withdraw if they so wished, and because individual work made it possible for a diversity of options to be a reality.
- Without a relationship of trust learners may be most unwilling to try out processes with which they are not familiar or which they do not fully understand.
- Professionals need to consider how to communicate a full range of possibilities and options to learners who may be quite unaware of the existence of some of them. The interests of learners are not best served by denying them the information available to professionals, although the forms in which such information appears may be alienating.

Choices 1

Self-advocacy clearly involves the ability to make choices for oneself. This section will look at two aspects of the professionals' work in this area:

- encouraging learners to make choices;
- how best to support them in sustaining and dealing with the implications of these choices.

Case-study D. Debbie and the self-assertiveness group

Situation

In working with a group of eight learners aged 18-40 and with severe learning difficulties, one of Debbie's main concerns was to find ways of encouraging them to make conscious choices, and to communicate those choices clearly. Several group members had difficulties with speaking and all were extremely diffident in communicating. This course was part of a programme directed towards people with severe learning difficulties in the community, and aimed at improving not only their skills but their quality of life through the provision of meaningful activities. However, Debbie, as an FE lecturer, was not directly involved in any other aspect of the group members' lives. Any choices that she offered could only be as a result of her own planning within the group.

Strategy

Since a first essential was to encourage the group to speak for themselves literally, Debbie implemented a programme of warming up activities that focused on this basic skill. Many of these exercises were adaptations of commonly used ice-breakers. These were repeated over the eight months and followed a rough sequence.

Some of the most successful involved each group member in:

1. saying their name
2. saying their name loudly and softly
3. saying each other's name
4. saying, then shouting, 'Yes' and 'No'
5. guiding another blind-folded learner around a chair
6. opening an imaginary 'magic' box, miming the use of an imaginary object they found inside it and then handing on the box to the person who guessed the object

7. having a group 'yell'

Debbie also provided choices in other ways. She ensured a choice of materials by:

- mounting an expedition to purchase attractive ring-binders for the portfolios;
- making available different coloured card for backing;
- using a variety of magazines for cutting out pictures;
- offering a range of glitter, papers, colouring materials, etc. for making Christmas cards.

Some of the activities she devised involved the group in making choices about what they liked best, albeit in an imaginary form. Many of these processes had a recorded outcome that formed part of their portfolios. Topics the group considered included:

- Drawing up a week's timetable of favourite activities, using colour-coded gummed paper squares to stick on a prepared chart.
- Choosing adhesive labels to represent themselves (sister, brother, son, daughter, Mr, Mrs, Miss, student, British, etc.). This exercise provided refusals as well as acceptance and generated some additional ideas, 'bachelor' and 'married' being two.
- Choosing how they would like their bedroom to look, using paint colour charts to overcome learners not knowing the names of the colours, magazine pictures and simple plans to do it. Debbie recorded, 'Mark could not choose his "ideal bedroom", just kept describing what he had. When I asked him who had chosen what, e.g. the carpet, he said, "My mum", but when I asked him what colour would he choose, if he could, he still said "grey".'
- Using the *Life of My Own* video as a basis for discussing with whom they would like to live. Two of the four women in the group, both in mid-life, said they would like to stay with their parents, but most of the men wanted to live with girlfriends or partners.
- Talking about what sort of holiday they would enjoy, which also revealed how lack of real experiences hinders the ability to make choices.

Other forms of choice gave group members the chance:

- to choose people to work with. This varied from the simple giving of an 'attribute' card (e.g. someone with a nice smile) to another group member, to picking a partner from a group of 'mainstream' PCSE students to make a Christmas card with;
- to choose between such activities as finishing a group collage or working on individual portfolios;

- to decide which warming-up exercises to start the session with. The crucial response to this was 'don't mind', leading Debbie to the conclusion that the group was usually more proactive if the choices were offered later in the session and that they needed an initial impetus provided for them;
- to make suggestions about future areas for the group to work on. This was slow to develop, but by month four one member had offered to host the group's visit to his home, and another suggested looking at leisure activities;
- to organise taking turns in using the camera, and being photographed or videoed.

In addition to all these consciously sought contributions, Debbie found she needed to stay alert to the implications of comments and non-verbal signals from the group. The youngest woman learner, by far the most able member of the group, found some of the issues about home life potentially distressing. There were also a number of occasions when topics with a sexual content arose, and this indicated a need for the group to talk about intimacy, the difference between public and private behaviour, and relationships with the same or opposite sex.

Lastly, although Debbie had no influence over the real-life decisions of any of this group, she did try to ensure that they had some knowledge of the options available. She did this through arranging visits so that the learners could see different situations for themselves. The places visited were:

- a very large day centre which had a long history of contract work and which has only recently instituted a students' committee
- a second day centre which has, from its inception, been run on self-advocacy principles
- the group home run by a national voluntary organisation where one of the learners lived. This was a house near the college, situated in a pleasant street and indistinguishable from its neighbours.

Dilemmas and resolutions

Working within these well-defined limits, Debbie did not encounter dilemmas connected to areas that were outside her influence that are common to much self-advocacy work. However, there were problems in offering choices in this way. This style of group work, particularly with people with severe learning difficulties, does demand a high level of attention to each learner. Decisions also had to be made about the amount of material gathered for the portfolios that demanded skills in reading and writing. This raised questions both about its significance for the group members, and the degree of help needed in order to facilitate it. Debbie was fortunate in being able to enlist the help of a very competent volunteer assistant for several months of the project, who was able to give additional support and encouragement to the learners, especially in pairs or in small-

group work involving interviewing or discussion. She was also able to help with writing and spelling as only two of the learners could write a little, with the rest being able to copy a little. When this volunteer left, Debbie was fortunate in being able to replace her with a student nurse for mentally disabled people who was with her on placement as part of her course. This additional staffing also gave time to review the portfolios individually with the learners, to help them recognise the contents and to feel some sense of ownership. On the whole, however, the portfolio contents depended substantially on materials that Debbie prepared in advance, leaving the learners with only minimal literacy tasks. Photographs, pictures and charts made up the other media used.

Developing this kind of programme demonstrates the role that education can play in encouraging the skills and use of resources learners need in beginning to use self-advocacy.

Tasks and skills

- Structuring and pacing sessions to allow for a variety of experiences and activities.
- Organising equipment, preparing materials and planning visits.
- Careful planning to match the content of sessions to short- and long-term goals. Choices offered within the course had to help promote Debbie's other goal of opening up possibilities of wider adult choices and roles.
- A knowledge of resources that provide ideas for games, and exercises that can be adapted and simplified to the purposes of self-advocacy. (Canfield and Wells, 1976; Brandes)

Attitudes and qualities

- Flexibility to ensure that learners' choices and suggestions can be accommodated.
- An awareness of the principles of self-advocacy and a willingness to explore adult issues with learners with severe learning difficulties.
- An expectation that learners can and will respond to new forms of stimulus and motivation.

Issues

- Lecturers in FE may not be involved in promoting real-life choices for the learners with whom they work, but they can play a role in developing self-advocacy skills among groups of learners. Such work is likely to be slow, long-term and demand considerable sensitivity and skill.
- Professionals using portfolio preparation in the development of self-

advocacy skills need to seek mechanisms which will help portfolios to be used as a way of securing change.

- For learners with severe learning difficulties in particular, there are issues to be considered about the presentation of the portfolios. To retype entries and to give considerable help with their arrangement certainly results in a more 'professional' and presentable product. This must be balanced against the view that to do so devalues the learners' own efforts, and might even undermine their self-esteem.

Choices 2

Members of the group that Debbie worked with found making choices very difficult. Her main task was to create opportunities for them to make choices. The second case-study takes up the theme of choices and in looking at the other side of this process examines the role of the professional in supporting a learner who is already able to make choices, and who is in the midst of some life changing decisions.

Case-study H. Harriet and Penny

Situation

Harriet is a young Day Care Officer at Fieldview, a newly opened resource centre for disabled people. The centre's philosophy is based on the principles of normalisation. Penny is among the first group of disabled people to come into the centre. She is 26 years old and lives at home with her parents, as well as with her brother and her sister who have both established independent lives. After leaving school she spent two years at a residential college for young disabled people and then seven years at a day centre. She has cerebral palsy, uses a wheelchair and will always have substantial needs for help with personal care. Before the start of the project she had begun to attend a professional computer training workshop, Brook Vale, run by a national voluntary organisation. This organisation also provides purpose-built or specially adapted houses for people with severe physical disabilities so that they can live independently but supported by the appropriate degree of personal and physical care. Penny has made the decision to leave home in order to live in one of these shared houses with two other disabled young women.

Strategy

Harriet saw her main task as providing the support Penny will need in sustaining these life-changing choices. Her goals were to involve Penny in

identifying the skills she will need to acquire, and in building up a satisfying programme of activities while Penny waits for the building alterations to be finished on her house. Harriet felt that portfolio preparation would help Penny in assessing her own skills and abilities and in presenting herself for future employment as well as supporting her in her transition to independent living.

During months one to five of the project Harriet and Penny drew together various items for the portfolio that arose from Penny's activities. These included:

- a life history, originally written for public display at the Brook Vale Workshop
- publicity material produced for a Physically Handicapped and Able Bodied (PHAB) club which Penny was instrumental in establishing
- a tape of a radio interview Penny gave in connection with the PHAB club
- information about the living scheme which Penny was to move to

Harriet also worked with Penny to improve her independence skills, including personal care, budgeting, shopping, cooking and mobility with her electric wheelchair. She also encouraged her to become part of the management committee at Fieldview. Towards the end of this period, Harriet began to express anxiety about Penny, who described herself as feeling confused. The uncertainty about the precise date of her move to her new home at Brook Vale intensified natural anxiety about such a major move. Penny talked a great deal about how strange it would be not to have her mother on call at night. From Harriet's point of view Penny seemed to be lacking in concentration, and unable to complete tasks she had undertaken, such as the PHAB club minutes.

Dilemmas and resolutions

At this point an entirely unforeseen event threw Penny's choices into doubt. The voluntary organisation closed down the computer workshop, giving no prior notice to its users. This not only disorganised Penny's life, but removed one of the ways in which she had seen her future developing. The same organisation also owned the accommodation into which she was planning to move, and this closure severely undermined her confidence in her future plans. Harriet recorded the situation: 'Penny had a strong reaction to the closing of Brook Vale. It was difficult to talk reasonably. Penny was overcome with emotion (anger, sadness, etc.) so I let her express her feelings openly....The worst thing that happened for me was thinking about how I would be able to offer Penny alternatives. I learnt that there is no such thing as security of day placements.'

Penny's response to the closure of the computer workshop was to campaign for its reopening. She was not interested in looking at what other possibilities for daytime activities there might be before her impending

move. At an individual programme plan meeting held shortly after this, it was agreed that Harriet should try to develop a structured timetable to fill up Penny's week, although Harriet notes: 'Penny was completely negative to any alternative suggestions to Brook Vale. Showed no motivation to do anything at Fieldview.' Harriet's next log entry reported that she felt 'extremely angry' with Penny over issues of keeping to arrangements and following through her agreed programme. This arose in part because it was Harriet who had organised some of the activities in which Penny was then not taking part. Harriet felt she could not support Penny in doing 'what she wanted to — nothing'. For her part, Penny described herself to the project officer as feeling 'bitter' and, again, 'confused'.

Harriet faced a complex task in supporting Penny through this difficult period of transition. Penny's attachments to her home and parents — attachments which are usually weakened or re-established on a different basis during the late teens of most people — had been strengthened by a further decade of dependency. The situation was then made immeasurably more difficult by the closure of the computer workshop and its practical and emotional impact on Penny's life. Harriet found herself dealing with one of the central features of life for disabled people: their extreme vulnerability to decisions made by other people, who are often hard to identify, and over whom the disabled person has little influence.

Tasks and skills

- Developing Penny's independent living skills through practical experiences.
- Advising on possible other ways of developing independence, e.g. a residential placement for assessment for a new electric wheelchair.
- Negotiating with other professionals:
  - the adviser to the PHAB Club
  - the management of Brook Vale
- Liaising with Penny's parents, particularly her mother.
- Counselling skills.
- Creating situations where Penny could demonstrate her skills in computers and in portfolio preparation.

Attitudes and qualities

- Sustaining the relationship even through negative emotions.
- Willingness to examine the conflict between her own professional viewpoint and Penny's more personal reactions.
- Maintaining an ability to recognise the difficulties faced by disabled people, and not becoming an apologist for the inadequacies of the social support provided for their needs.

- Professionals need to consider whether there are any grounds that might cause them to withdraw their support for decisions made by a disabled person, and how this would then relate to their commitment to self-advocacy.
- There may be uncomfortable dilemmas for professionals if disabled young people want to exert their right — common to non-disabled adolescents, to be alone — to do nothing and to be what adults consider to be 'awkward'.
- There is an undoubted conflict between the professionals' concern with practical outcomes and with what they would see as realistic possibilities, and the young learners' concern with emotions and the need to assert themselves.
- The lack of a peer group for many young disabled people means that they have much less opportunity for testing out their ideas and opinions within a supportive atmosphere than do most young people. They also face making decisions that, because of lack of range of provision and opportunity, have more final implications than those made by other young people.

Adult roles

The importance of introducing learners to the sorts of adult roles from which they have been excluded has been emphasised. Perhaps most important among such roles is that of employed worker.

Case-study E. Elena and Val

Situation

Three years ago, Val, a young woman with moderate learning difficulties who is now 30, began a training course in catering with a national voluntary organisation. She followed this with part-time employment on a Community Programme and with further work on an Employment Training scheme, both also run by the same organisation. Before her involvement with this organisation she had spent ten years at home. Her three sisters have all left home to marry and have also achieved educational success, while Val lives with her parents and grandmother. Elena is in her late 30s and is the area officer for the voluntary organisation and responsible for the funding and running of its many activities.

Elena felt that the work of the voluntary organisation would benefit from a greater involvement with self-advocacy. From the beginning, she had a clear idea that, for the individuals associated with the organisation, this meant getting a job, and with it, self-esteem, status and wages. Val was invited to take part since her time with the Employment Training Scheme was nearing its end and she had said she wanted to look for work. Elena expected Val to take responsibility for the processes involved, and to produce materials for the portfolio independently. Most of the work was oriented to practical ends. After an interrupted spell at the beginning, they settled into meeting for about two hours a week at a variety of locations, including Val's home, Elena's office and the Job Shop.

The portfolio contents included:

- evidence of Val's attendance at a computer workshop
- photographs of cakes she had iced
- photographs of herself with friends
- pieces of writing including:
  - Val's Life Story
  - 'The Best Thing that Happened in My Life'
  - 'The Worst Thing that Happened in My Life': two letters telling her of unsuccessful applications, but giving positive feedback:

    'However, I have to tell you that you were **seriously** considered for the position and your interview gave a most positive picture of your character and abilities.'

Other material that was produced as part of the job-search process included records of:

- Val's ideas about employment:
  - 'it means you're doing something'
  - 'you're busier'
  - 'something interesting and new to do'
  - 'meet new people, maybe a boyfriend!'
  - 'you have to be on time'
  - 'probably have to be full-time'
  - 'would like someone to go with me to new place'
  - 'gives you more responsibility'
  - 'would give up if I didn't like the people I was working with'

— 'would need company'

- Her work experience and her own identification of skills she had acquired.

Dilemmas and resolutions

Two problems arose that hindered Elena's determination to treat Val as a competent adult and to offer practical support in the portfolio preparation and the job search.

The first was the high level of Val's anxiety and the way in which this was expressed; Val seemed unable to sustain any one topic. Elena reported in month four: 'I am beginning to get quite frustrated by straying off the subject. Looks like if questions uncomfortable then off the subject we go. Go back to question. Off the subject again. It was quite funny because at the end of the sessions I still haven't had the answer!'

Elena tried a variety of ways of handling this sensitive area, and maintaining 'normal' expectations of her interaction with Val. Finally she settled on a combination of using reassurance and the positive aspects of portfolioing to dispel the anxiety; she allowed up to half of each session for Val to 'offload' (a student need commonly experienced by adult education tutors); and she tackled the problem directly by pointing out digressions as they arose, and by suggesting techniques to stop Val 'twittering'.

The second area that created difficulties was that Val's parents felt well able to provide for her, and her mother and grandmother appreciated her company at home. They saw no need for her to go out to work. To help change the way her family perceived her, Val and Elena set the short-term goal of Val planning and cooking a meal for them. Although she was capable of this after her catering training, her role within the family as helper or assistant had become fixed. She depended on her family to provide transport. As an interim step Val made sure that she took home attractively cooked items from her placement, and Elena helped Val to use a bus timetable and to use the buses. Elena spent some time with Val's parents talking over what they were doing and why, but was left with the impression that they 'think we're pushing too fast'. Nevertheless, her mother and sister, when Val insisted, gave her some help in filling in an urgent application form, and were pleased, if surprised, when she started to get interviews.

Elena's approach was essentially practical. In searching for employment it became evident to Val herself what skills she needed to acquire. Elena found herself helping Val to manage anxiety that was now getting in the way of her progress. A very wide range of professional activities was involved.

Skills and tasks

- Introducing the learner to the local job market, and familiarising her

with the standard processes of job-hunting.

- Encouraging the learner to put into practice her undoubted competence.
- Giving time and attention to the learner's family to enable them to explore their attitudes towards her.
- Guiding the learner in preparing entries for the portfolio.

Attitudes and qualities

- Consistency in regarding Val as an autonomous adult with the potential to change and develop.
- A strong orientation to practical outcomes and knowledge.
- A tenacity in finding ways and means to circumvent difficulties.

Issues

- Professionals must be aware of the difficulties of promoting the goal of employment within a highly stratified job market. There is a marked increase in low-paid, part-time, casual work, which does not have the benefits of sick pay, pension rights, or trade union protection. Professionals need to beware of inadvertently putting pressure on disabled people to accept exploitative working conditions because that is all that is available.
- Professionals may also find themselves in a difficult position if the middle-class parents of young disabled people find unskilled work unacceptable for their adult children.
- Many disabled people face lives that are made exceptionally difficult for them by pressures from society and consequently have high levels of stress and anxiety. For those with learning difficulties, cognitive problems may interfere with the development of a sense of understanding and control over events. It is appropriate for professionals to consider how best to develop interpersonal skills and how to teach techniques of stress management such as relaxation and breathing.
- In our society, without a job it is difficult to meet a variety of people and to acquire the social skills and self-confidence that enable an individual to get and hold down a job in the first place.

Sharing information and skills

Professionals must learn to share their information and skills so that

learners can take more control over their own lives. As this case-study suggests, this is not always a straightforward process.

Case-study J. Jane, Jenny and the People First Group

Situation

Six months before this project began, Jane, the social worker in a Community Mental Handicap Team, went with two people with learning difficulties to the National 'People First' Conference in London. As a result of this experience, they decided to set up a local People First group and to organise a similar conference for attenders at four local social education centres. Jane agreed to act as adviser to the group, and guided it through the organisation of the conference. She then wrote a report on the proceedings and submitted it to the Director of Social Services.

The group members, who had moderate to severe learning difficulties, all attended one social education centre (SEC), which provided transport for them to a building run by an educational voluntary organisation where the People First group met at fortnightly intervals. Since Jane was not a member of the SEC staff, she was able to act as an independent adviser. Unfortunately, in month two of the project she was obliged to commence a period of three months sick leave, returning in month five. In the interim her place was taken by Jenny, an occupational therapist from the same Community Mental Handicap Team, who continued to work with Jane on her return. The significance of this interruption was that both Jane and Jenny had to go through the process of getting to grips with the contradictory demands of becoming an adviser to a self-advocacy group, particularly the questions of how best to share their skills and information with the group.

Strategy

Part of Jane's understanding of her role was to use her professional knowledge to create ways in which users' voices could be heard in the planning and decision-making processes of the services. It was to this end that she submitted the report of the conference. However, such moves are long-term and slow moving so most of her work was focused on the actual support of the group in its meetings and other undertakings. Having witnessed the abilities of people with learning difficulties to speak for themselves and seen the issues raised at the local conference, Jane felt confident that, given the opportunity, the group could and would identify areas where they wanted to see change. She therefore saw her role as non-directive and as offering advice and information when the group indicated it was needed. She reported:

'Bob sought advice on a cash book and how to organise this. I showed

him and the whole group how to lay out a cash book. The group's finances were counted in front of the group and entered. Paul (the chairperson) was given 50p to buy stamps from the Post Office machine round the corner. As he had not experienced this before, I agreed to go along with him.'

She also came to see the need to give the group clear information on their rights.

'Towards the end of the meeting the transport driver appeared at the door. Without comment the meeting rose as one (in the middle of a discussion) and put their coats on. I advised them that they could carry on with their meeting and that the driver could wait. They sat down but were obviously uneasy.'

Both Jane, and later Jenny, looked upon confusions and mistakes not as evidence that the group were incapable or 'not ready' but as indicators of the skills they needed to learn or of the experiences they lacked. This was in contrast to the SEC staff who wrote regarding one retrievable confusion: 'It must be emphasised, therefore, that people in the group are not yet fully prepared to accept unrealistic (sic) assumptions about any support they need in order to fulfil their aspirations.'

Jane and Jenny's initial strategy was that given the opportunity and with the help of their advice (itself a resource), the group would learn through direct experience how to organise themselves and choose goals to work towards. They felt the direction the group took must arise from the concerns of its members. When the group undertook the 'maintenance' activities that were already within their own experience, they quickly learnt to function well. A small weekly subscription was collected, tea and coffee ordered and paid for, biscuits provided and, with help, a Christmas coffee morning for 70 organised. The group also devised a logo and with Jenny's help made silk-screened membership cards. They started to plan for a second conference and the chairperson attended the local Social Services Development and Planning group. This was a direct result of Jane's conference report. By month five a visitor from a citizen advocacy organisation commented upon the way the group cared for each other, and listened attentively to each other when they spoke.

Dilemmas and resolutions

It became increasingly evident that the group had no background experience in:

- the protocols of running a meeting:
  - roles of chair, secretary, treasurer
  - agendas
  - minutes
  - addressing the chair

  - taking turns to speak
- organising:
  - the time-scales involved
  - how to identify all the tasks
  - the allocation of tasks
  - setting goals
  - full consultation over decisions.
- basic skills:
  - letter writing
  - minute-taking
  - handling money
  - making small purchases

Members also had some difficulty in separating the work and relationships that arose within the group from interactions outside it. Conflict from other areas of their lives was sometimes brought into the group and at other times: 'some members of the group are getting together outside the meeting-time and are arranging or deciding things — this causes confusion when we do have a meeting because other group members cannot follow what they are talking about' (Jenny). Of course, neither of these features are unknown in the workings of many committees, but then their members usually have the sophistication either to conceal them or to use them as conscious strategies.

It also became clear that the group members would not spontaneously link their individual concerns (such as having second helpings available at dinner, being able to watch TV after 11pm in their own room, or being delayed in returning home by the driver staying to chat with staff) together so as to identify wider issues. They had little concept as to who made the policy decisions which affected so many aspects of their lives, or who was responsible for managing their implementation. The idea of openly taking positive action to effect change was not part of their thinking. In common with many powerless people, they were astute at using those with more control and influence to speak on their behalf. On more than one occasion members of the group misrepresented Jane or Jenny to other members of staff or vice versa.

Over the months Jane, and then Jenny, recognised that being directive is not incompatible with promoting self-advocacy and that there is a sequence to go through of directiveness, sharing and relinquishing control. By month six they reached the decision to increase the frequency of the group meetings to weekly, using alternate weeks as skills sessions during which they focused exclusively on formal group skills, basic education and group development. Throughout the project the question of portfolios had

been considered as they seemed to offer a focus for work, as well as increasing members' sense of self-esteem and personal effectiveness, but it was not until this point that it became a feasible proposition.

It may be useful to look in more detail at the experience of Jane and Jenny in advising this 'People First' group, and the implications of this for other professionals.

Skills and tasks

- Advising on the running of the group:
  - intervention through tactful questions: 'Is there something we've overlooked here?'
  - keeping the group on task and to the agenda
  - reminding the officers of their roles and responsibilities
  - providing pictorial agendas
  - taking back-up minutes
- Advising on the substance of group discussions:
  - identifying and separating general issues from individual ones
  - recommending courses of action, e.g. joining National People First — bringing relevant news items — local and national — to the group's attention
  - suggesting speakers for areas in which the group needs more knowledge
  - clarifying decisions and goals
- Providing information about which steps are necessary to achieve specified goals:
  - who or which agency to approach for different purposes
  - general means for promoting special interests, e.g. letter-writing, press-releases, newsletters, conferences, etc.
  - how to apply for grants and funding
- Teaching or providing skills of:
  - reading
  - writing, particularly for letters
  - simple bookkeeping
  - producing promotional material, e.g. membership cards, letterheads
  - opening a bank or savings account

- Creating opportunities for 'People First' to be heard:
  - involving management at highest level
  - supporting chairperson at Local Development Group meeting
  - ensuring that the group minuted decisions and opinions on significant concerns
  - drawing attention of management to People First's views
  - seeking funding for local conference.

Attitudes and qualities

Many of the skills Jane and Jenny used evolved not just from their orientation to particular tasks, but also from their basic attitudes and personal qualities. These included:

- Positive regard for the learners which showed itself in:
  - tact in offering advice without impinging on the group members' self confidence
  - sensitivity in judging when to be directive, and when to stand back
  - consistent support for the group's self-organisation, even when it fell short of professional standards
- Faith in the learners' ability to learn and develop:
  - ability to discern progress, even when it was limited
  - a commitment to experience-based learning
  - the patience and confidence to repeat and reinforce learning as often as necessary

Issues

This work raised issues which extend beyond the specific role of adviser to a People First group.

- Groups organised solely around self directed activity may not, by themselves, sufficiently counteract members' difficulties which arise from lack of experience and opportunity to take on limited adult roles. This is why the role of adviser is so crucial.
- There seems very little discussion among professionals as to how to manage a transition from being directive to being supportive or sharing, and then to standing back and letting the learners take control. What signs indicate the need for the professional to shift their role?
- Although people with disabilities may now be represented within the planning processes of agencies and institutions, these procedures continue to be professionalised, formal and intimidating. Could they be

made more 'user friendly' so that the voices of disabled people can be heard?

Working with mistakes and disappointments

The way in which professionals understand and respond to mistakes and disappointments depends on what kind of people they are. The importance of the key workers' attitudes and commitment became very apparent in the course of the project, and particularly in the case-study chosen to illustrate this theme, which concerns a learner with profound and multiple disabilities. In work of this sort, it is the professional's own perceptions and commitments that provide the incentive to initiate change and the stimulus to continue.

Case-study F. Frances and Jonathan

Situation

For meeting all his basic physical needs — feeding, washing, toileting, dressing, mobility — Jonathan is entirely dependent on the staff of the hospital where he lives. His means of communication are non-verbal vocalisation, facial expression, limited body gesture and his personal manual signs for 'yes' and 'no'. Frances felt that, nevertheless, he had good **understanding** of speech. Jonathan lives on a ward with other residents who have profound and multiple disabilities and who do not communicate easily. He also has some degree of visual impairment. Since he cannot speak or sign for himself, not only are the major decisions made for Jonathan but all the small, daily ones as well. He has been in the hospital for over 20 years, since he was about ten years old. His parents still visit regularly and Jonathan enjoys this visibly. For most of the time, however, Jonathan is on the ward, with weekly sessions of hydrotherapy. He also attends a group at the hospital's Continuing Education Centre which is staffed by the local FE College and this is where Frances works.

Strategy

Frances recognised that Jonathan was not offered choices on a day-to-day basis, and that, whatever he did or indicated, it had very little real impact on his life. In other words, he had little opportunity for discovering the consequences of deliberate behaviour. He certainly displayed interest, liveliness and pleasure on occasion, as well as appearing withdrawn, moody and depressed at other times. As far as Frances could discover he had never been offered choices which had clear results. It was this gap

which Frances set out to fill, together with an exploration of his likes and dislikes, both about the past and the present. She also envisaged building a portfolio as a record of the processes involved as well as of any of Jonathan's preferences that might be discovered along the way. Besides the weekly group meeting, Frances tried to see Jonathan on other occasions during the week and to find the time to liaise with his parents and other staff.

Since Jonathan is very responsive to music, Frances marked out this as an appropriate starting area. She describes her first attempts in month one:

> 'I read out several titles of cassettes to which he signed "No" until I came to Dire Straits to which he said "Yes" — he was very definite and would not be dissuaded. However, when I actually put the tape on, he changed his mind, perhaps realising it wasn't what he'd expected. He was very insistent that I should change it but I insisted that as he'd chosen it he should have one track before I changed it, which he certainly seemed to understand and waited for.'

Over the months Frances ensured that Jonathan knew the titles of various pieces of taped music, and offered him repeated experiences of choosing between them. By having to abide by the consequences of his mistakes, and being rewarded for correct choices, Jonathan built up a repertoire of these tapes and could reliably indicate which one he wanted to hear.

Frances also used the portfolio to build up a list of his likes and dislikes about food and activities, and his memories of the past. She used his strong ties with his parents to develop his communication skills, arranging phone calls to his mother — a new experience for him — to encourage vocalisation, and introducing the Makaton sign for phone.

Dilemmas and resolutions

The work with choosing music was straightforward and under Frances and Jonathan's own control. Other aspects required the co-operation of others, especially when she sought information or memories about the past.

There seemed various impediments to collecting this information. She reported: '...it's difficult to pin the ward staff down — they seem not to consider it of importance and records are very skimpy.' Despite Jonathan's many years in the hospital, it was difficult to identify who had known him in the past and to evoke memories of any specific incidents from them. His parents were initially enthusiastic about producing photographs and reminiscing about Jonathan's early life. His mother, however, clearly came to find the phone calls difficult, perhaps because of the lack of verbal communication. Unlike Frances, she could not see his enthusiastic signing in answer to her questions. Perhaps it also signalled a change in the balance she had achieved in her life and in her perceptions of Jonathan. On one or two occasions Jonathan had to cope with disappointment when his mother did not answer the phone, although he enjoyed hearing it ring.

Further difficulties arose when Frances realised that Jonathan was unable to recognise even enlarged photographs. Writing and posting a letter to his sister, requesting a current photograph, and an extended tour around the hospital to photograph places that he felt were significant had been stimulating and exciting exercises. This was more disappointing for Frances than for Jonathan since she had hoped the photographs would give him some way of recalling people and the past. It was as a result of this that she sought to tape-record other people's memories about the past so that Jonathan could enjoy listening to them.

Despite these difficulties, a portfolio was assembled. Although it was of little independent use to Jonathan, it did enable other staff to find something to communicate about, and appeared to affect their attitude to him.

To seek to develop self-advocacy skills with Jonathan was seen by many of the hospital staff as an act of misplaced faith. Certainly the work arose out of Frances's conviction about his inherent worth as a person. Without this fundamental belief she would not have been able to envisage the possibility of change or to devise appropriate activities. This lack of a belief in change in other professionals had been encountered by Jonathan and had contributed to the powerlessness in his life, and the lack of opportunity to develop his potential abilities.

Tasks, skills and attitudes

As has been suggested, these were inextricably combined in the work undertaken in this case-study. A number of areas can be identified.

- Communication:
  - giving Jonathan the time and attention needed to identify his interests and enthusiasms
  - persuading nursing staff to co-operate in checking for further aids that might be useful
  - involving Jonathan's parents in portfolio production
  - convincing ancillary staff and student nurses that time spent over offering and making choices was not wasted
  - finding a variety of physical techniques to stimulate and make contact with the learner
- Teaching:
  - motivating Jonathan by building on his interests and abilities
  - identifying and teaching the simple steps that build into the complex skill of choosing
  - using a variety of resources: music, signs, photographs, tapes, telephone, trips in Jonathan's wheelchair, etc.

- using empathy so that Jonathan grew to know it was worth the struggle to communicate: 'If I don't ask the right questions then Jonathan has no chance of saying anything.'

- Innovation:
  - applying the principles of self-advocacy and portfolio preparation in new and appropriate ways
  - having the vision to create attainable goals
  - refusing to allow the existence of profound and multiple difficulties to determine the outcome

Issues

- It is the existence of positive and creative attitudes among professionals that makes self-advocacy a realistic goal for young people with profound and multiple disabilities.
- Disabled people, especially those in institutions, are further deterred from facing the future with confidence when they own no sympathetic record of their past. This becomes an even sharper difficulty when they no longer have any family to help them recall or record it.
- Even if it might be argued that there are disabled learners who could not potentially benefit from the process of developing a portfolio, it seems likely that there would be positive results from having it developed for and with them, and from having it made available to others.

Taking risks

Since self-advocacy is about change, risk taking is an inevitable part of encouraging its development. It is also true that when disabled people do get access to the adult roles and activities from which they have been excluded, the timescale in which they have to complete the transition to adulthood is often compressed. There is not the extended period of adolescence available to many non-disabled people. This means that they are under pressure not to make mistakes but, because of this pressure, may well do so. Risks are therefore a reality. It is not only disabled learners who are being invited to take risks; parents and professionals too face challenges to their established positions.

Case-study I. Isabel, Ivor and Edward

Situation

Ivor, further education lecturer with responsibility for deaf students, and Isabel, a social work assistant with a social work team for deaf people, had chosen to work with Edward, who is about 20, profoundly and pre-lingually deaf, and mildly affected by cerebral palsy. From the very beginning, in the first session when they explained the idea of self-advocacy to him, Edward had been able to define his own aspirations. He wanted: his own flat, to be a good cook, and to learn to drive a car.

Strategy

Ivor and Isabel accepted these as wholly legitimate goals and planned a programme for and with Edward that included the overall long-term aims for Edward of open employment, passing the driving test, independent living and personal skills. The shorter term objectives were:

- Personal knowledge:
  - personal hygiene
  - sex education — contraception, VD, Aids
  - self-awareness including knowledge of cerebral palsy
  - assertiveness training
- Deaf culture:
  - organisations for and of deaf people
  - use of interpreters
  - welfare rights
  - Deaf Club and contact with deaf people
- Life skills:
  - mobility: road safety, bus routes, fares, timetables, knowledge of locality
  - shopping: communication, money, identifying correct shops
  - home maintenance: cleaning, budgeting, mending fuses, cooking, washing and ironing
  - driving aptitude assessment

To these were added:

- computer and keyboard skills
- development of British Sign Language
- work experience

It was also clear to Ivor and Isabel that working towards these goals would have a considerable impact on Edward's daily life. They therefore decided that it was essential to involve Edward's parents, especially his mother, in the work. Nearly every aspect of their understanding involved risks of different sorts.

Dilemmas and resolutions

Several issues arose in the course of the project that the key workers felt were risky. They demonstrate the variety of risk taking that self-advocacy work can involve learners and professionals in.

Edward had no experience at all of independent mobility, had never used buses or trains, and at 19 very rarely left the house by himself. Introducing him to independent travelling, crossing roads, finding his way, dealing with bus routes, timetables and fares, all therefore involved real elements of risk — either of his getting lost or stranded, or, more seriously, of physical injury on the roads. Edward's mother, herself disabled, found this enormously worrying — 'she was in contact with Isabel twice this week over her fears of Edward using public transport, saying that he would not be able to cope with the situation'. The key workers' response to this was twofold. First they ensured that they gave Edward carefully graded and monitored tasks so that the risk was reduced to a minimum, and secondly they took his mother's anxieties as warranting respect. They not only listened to her, but explained in detail what they were going to do, how and why. They made sure they always fulfilled any undertakings they made to inform or visit her. In this way they established sufficient trust for her to guide them by saying that there were some activities she didn't mind Edward doing — but she didn't want to know about them till afterwards.

At this time Edward's mother still involved herself in matters of his personal hygiene; due to her disability, he also helped her into the bath.

Edward himself had no access to, or control over, the disability benefits he received, although his mother did pay some into a separate savings account on his behalf. Since his father was unemployed, the money contributed to the family income was quite significant. Apart from the £1.70 'earned' at his placement at a horticultural unit for adults with learning difficulties, Edward had to ask and account for all other money. Edward's lack of peer-group support, inexperience of travelling alone and lack of opportunity to develop survival skills, all meant that his parents exercised much greater than average control over his life. The key workers feared that if the project work threatened this parental control too abruptly, Edward might be prevented from continuing. They also felt that some of these practices needed to be challenged directly. 'Edward's mother denied that she looked

after Edward's money and we pushed the issue as far as we could without endangering our relationship with her.' By proceeding gradually and reminding themselves that Edward's mother also had a legitimate right to her point of view, as well as grounds for holding it, the key workers raised a wide variety of sensitive and contentious issues. At times they felt underhanded in not immediately spelling out the long-term goals they had developed with Edward, but as his mother came to have confidence in them they were successful in putting most of them on the agenda.

The key workers acted in a confrontational manner with Edward himself on several occasions, risking a rupture of their own relationship with him. Once Edward had identified a course of action and made an agreement about it, Ivor and Isabel had been firm about his responsibility to carry it through. In month two he refused to go on a planned shopping trip, having recently been for a Mobility Allowance interview and gained the impression that he was not allowed to walk. The key workers' response, after going over his grounds for refusing several times, was to leave him behind and set off themselves, as agreed. Under these circumstance the strategy presented little risk. More was at stake, however, when Edward began to want to leave a new work placement each day before the agreed time. By month five Edward had negotiated a place for himself at the college where Ivor worked and had left the horticultural placement. He had expressed interest in, and had succeeded in, getting a work-experience place in a unit which prepared cook-chill food, and which also employed deaf users of BSL so that he had company. After initial enthusiasm and demonstration of a number of competencies in his interview and in getting himself to work on time for an early start, Edward lost interest. He began to leave at 2pm instead of 3.15. Management told him this was not acceptable and Edward made enough of a scene for Ivor to be contacted and alerted to the difficulty. The older deaf workers also intervened, telling Edward that everyone found the work boring, so why did he think he was so special? Ivor and Isabel felt that Edward was entitled to leave the placement if he wished, but that he needed to be fully aware of the consequences if he did so. Ivor told him clearly that the placement was part of his college course and if he left it he would not be able to continue with the college-based elements either. This meant that his choice was between fulfilling his duties properly at the cook-chill unit, or returning to doing nothing at home and losing all contact with the project. There was a real risk that Edward might have chosen the latter option if he had been pressed further, but Ivor reported:

> 'I told him that I was so angry that I was leaving the room to calm down and would return and expect a decision from him. On my return he decided to agree to go (to the cook-chill unit) but I told him he decides and if he wanted a future of his own he must understand the consequences of his actions.'

Practising self-advocacy is likely to generate the need to take risks. These can be the risks of physical injury to the learner, the risks of provoking uncontainable conflict, and the risks, not raised here, of being judged

unprofessional and, at worst, becoming subject to disciplinary procedures. Although the risk element cannot be totally eliminated, sensitive planning can certainly reduce it. An identification of potential risks is essential if such work is to be undertaken.

Assuming adult roles also means assuming adult responsibilities, an area in which young disabled people may have little experience. They may have been well cared for and protected, but are rarely challenged or put in situations where the actual consequences of decisions and actions have to be met. It is a difficult line for professionals to tread: between supporting learners but confronting them, and between understanding the reasons and grounds for their difficulties and behaviour, but insisting on high expectations and standards.

Tasks, skills and attitudes

Together, Ivor and Isabel developed the following practices:

- Planning for activities that involve physical risk:
  - careful grading of stages
    - demonstration of practice
    - guided practice
    - observed practice
    - shadowing
    - independence
  - support through each stage
  - monitoring each stage
  - providing 'fail-safe' measures where possible, e.g. an identity card with journey details
- Gaining parental consent and confidence:
  - clear and full explanations
  - complete reliability in fulfilling undertakings
  - recognition of validity of parental viewpoint
  - provision of support for parents, e.g. phone calls, visits
  - listening to, and learning from, parents
  - negotiating activities and timing
- Risking conflict with the learner:
  - giving clear information about agreements
  - being consistent

- spelling out the consequences to different options
- supporting the learner in all agreed undertakings
- supporting the learner in gaining her or his rights, e.g. to have an interpreter
- making clear the limits of professional power
- making it clear that professionals do have power and explaining how and when it might be used
- recognising their personal investment in the learner's success
- accepting that anger and conflict are not necessarily harmful

- Minimising professional risks:
  - consultation
  - clearly defined goals for each stage
  - records of consent sought and gained
  - gaining clear management support
  - being accountable for professional activities and decisions

Issues

- Self-advocacy puts into question the nature of the rights professionals claim in taking responsibility for those in their care. Who is entitled to make decisions about the way disabled people live their lives? They may prefer the option of more freedom or mobility, even if it means greater risks. Self-advocacy implies that disabled people should have the same liberty to undertake dangerous activities as any other adult.
- Since professionals do have real power in the lives of those they work with, clear statements about its existence and the limits of its use are helpful.
- There is a need to be clear about the processes involved in being directive, sharing and letting go.
- Professional supervision and guidance is essential as a way of offering security for workers and also of minimising the risks involved to everyone.
- A recognition that young disabled people have often been protected from taking risks, and so may not have the experiences to enable them to judge degrees of risk.
- Parents' perceptions that young disabled people do face greater social, emotional and physical risks should not be dismissed. How can these young people be afforded the protection they legitimately need without encroaching on their autonomy?

Extending the professional repertoire

This account is particularly concerned with the changing roles of professionals and a redefinition of their accountability. It looks in greater detail at how two of the key workers – Gayle, a further education lecturer and Bruce, a community worker – found it necessary to learn ways of working that would extend the repertoire of skills and attitudes specific to their own profession.

1. Case-study B. Bruce and Harry

Situation

By month six of the project, Bruce had seen Harry well settled in his own flat, with benefits, budget, furniture, decoration, cooking and other household tasks all sorted out. Bruce was visiting much less frequently and at Harry's invitation. It was at this stage that there was greater opportunity for putting together a portfolio. Neither Bruce nor Harry was deeply committed to the idea at this stage, but they were willing to try and a start was made.

Strategies

Up to this stage the focus of Bruce's work with Harry had been the practicalities involved in re-establishing him in living in the community after a number of years in a psychiatric hospital. Bruce had also encouraged Harry to understand and claim his entitlements to benefit. There had been a major disappointment when Harry's application for a resettlement grant had been disallowed on the grounds that his income was 20p a week too high. Bruce had supported Harry in a visit to his MP to put his case, after explaining that it was not likely to help Harry personally. Nevertheless Harry was determined to go ahead, although really quite intimidated by the prospect. His pride in successfully accomplishing the visit was plain to see, as was the increase in his sense of dignity through undertaking something that might be of use to other people in a similar situation to his.

Dilemmas and resolutions

With Harry's agreement decisions were made to set regular time aside for portfolio preparation. Bruce established the use of a dictaphone and said that he would undertake the literacy component of any written recording, so that pressure on Harry would be reduced. Initially he seemed to enjoy talking about the 'old days', and offered to ask members of his family for any material that might be useful. Harry did not remember to do this.

however, and on the next occasion Bruce reported: 'Harry flatly refused to stay in his flat and do any work because the weather was so good...Harry quite clearly stated he was not bothered about the portfolio and I considered negotiation was not therefore appropriate.' By this time, the beginning of month seven, Bruce had come to feel that a portfolio could be an extremely important asset for the clients with whom he worked, especially in enabling them to represent themselves at reviews and case conferences. These events, while routine for the professionals, were momentous and intimidating for clients. The principles of self-advocacy certainly seemed to imply that it was essential for them not only to be present, but to be heard, and Bruce saw that a portfolio could be of help. He felt in a dilemma, however, about how to ensure that Harry kept agreements, and how to know whether he had made them freely in the first place. Bruce also felt he needed the skills to motivate Harry, to engage his interest in portfolio preparation and to find tasks and activities that would translate his memories, concerns and goals into an accessible form for others. Successful at befriending and motivating Harry where practical goals that Harry clearly understood were concerned, Bruce felt somewhat at a loss in promoting less immediate goals.

2. Case-study G. Gayle and Dawn.

Situation

The academic year was already underway when Gayle became involved in the project. This meant that self-advocacy work was taken on in addition to her existing timetable. Her sessions with Dawn were already therefore marked as different – both time and place had to be flexibly arranged, and Dawn was the only learner. Gayle had chosen to work with Dawn because she appeared to be unassertive and because they already had a friendly relationship. The initial sessions were spent in introducing the ideas of self-advocacy and portfolio preparation, beginning to discuss what might go into a portfolio for Dawn, producing a draft of personal information and using a word processor to make a fair copy. Within the context of an FE college, however, and as Gayle also taught Dawn on another course, she found it difficult to convey to Dawn that they were engaged in a different sort of relationship.

Strategy

Gayle was clear that self-advocacy work demanded something different of her from her usual role as teacher of students with learning difficulties. This was not easy to establish when she was meeting Dawn within the buildings of the college, and sometimes even in the same rooms that she taught her in. Gayle's approach was to emphasise explicitly to Dawn that the point of their sessions was for Dawn to take control of what they did with them.

Dilemmas and resolutions

Gayle's early reports repeatedly offered her view that Dawn was too easy to influence, saw Gayle as a teacher and had no sense of owning or directing the session: 'It is yet another "professional" relationship, one she is so accustomed to, and so can play her role well', and 'It seemed too much like a lesson'. Dawn was also very reticent about her past and seemed to have very little social life outside that provided by her key workers and the mother in the family which took her in on a placement during the major bank holidays. Although Dawn had her own strategies for directing the course of the sessions – 'side-tracking' as Gayle described it, for the first two months she gave few signs of being able to initiate, set goals, openly say what she wanted or even work alone. Gayle, meanwhile, was trying to find ways to hand over the sessions to Dawn so that, in this relatively safe situation, she could begin to find out in small ways where she wanted to go. Gayle began to use techniques she was learning on a counselling course and to acknowledge the difficulty she had, as a teacher, in loosening her control: 'I deliberately prepared nothing for the session, interested to see what would happen...though simultaneously I feel both guilty and anxious at having nothing prepared, as the lack of structure and the notion of time-wasting bothers me.' Gayle also began to appreciate the significance of Dawn's social situation outside college and to feel the need for better liaison with the professionals from Social Services who gave Dawn regular support. By month four Gayle was reporting that Dawn was 'full of thoughts and ideas'; 'at Dawn's instigation we began talking about the self-advocacy Day,(at another institution)' and that Dawn 'worked from her own initiative'. Subsequently Gayle increasingly moved outside the college with Dawn, going swimming with her and attending a silver-smithing workshop. She began to befriend Dawn and, through her own example of trying pastimes she found less easy, to motivate Dawn to extend her own range of activities.

Tasks, skills and attitudes

These two workers exemplify the self-reflective way of working demanded by the promotion of self-advocacy skills. They had to:

- monitor and reflect on their own practice;
- evaluate the use of portfolios for their learners;
- assess the needs of the learner;
- extend their own repertoire of skills;
- adapt their own reactions to fit in with the needs of the learner and the principles of self-advocacy;
- examine professional boundaries.

Issues

- Developing self-advocacy skills and introducing portfolio preparation calls for a shift in the power relationship between learner and professional, but not for the abandonment of professional skills.
- Professionals need to have a clear sense of the process and an ability to adapt their approach as the learner changes; directive and student-led methods all need to be part of their repertoire.
- Student-led and open-ended programmes also need to be dovetailed with professional knowledge about how learners can best affect decisions taken by others about their future.
- Institutional location will define the scope of a professional's role and the way in which the learner perceives it.
- Ways have to be found of managing the impasse that can arise when learners are resistant to taking on responsibilities or attitudes that the professional sees as necessary to achieve goals identified by the learner, e.g. being able to cope with case conferences; the social skills of intimacy.
- The ability to identify sometimes small changes is an important part of the professional role in work with people with special needs.

Boundaries and disclosures

Within self-advocacy work and portfolio preparation, questions arise as to how much learners should be encouraged to disclose about themselves. The aims of the professional should be to restore a sense of their own autonomy to the learners, not to subject further areas of their lives to scrutiny and regulation.

Case-study K. Kevin and Amrit

Situation

About half the learners who attend the special further education unit of which Kevin is Lecturer-in-charge, have a shortened life expectancy, and all of them have profound disabilities. The philosophy of the unit is that educational provision for this group of young people must take into account the learners' needs to look at themselves, their past, their expectations and their fears. Unless looked at, these concerns remain as blocks to learning. Kevin characterised the learners' immediate needs as

being for relationship, meaning, contentment and moral or spiritual answers. Young people in this situation also seem to the unit staff to consider themselves worthless, and to experience not only lack of a variety of roles in their own lives but also to have no positive role models to follow.

At the beginning of the project, Amrit was in his second year full-time at the unit, and would be able to stay for a third and final year. He had been successfully following some high-level maths courses and showed good academic ability. However, his physical dependency was increasing and it was very laborious for him to produce written material, even using an adapted computer keyboard. He was extremely reticent about his feelings and hesitant to make decisions.

Strategy

Kevin was struck by the disparity between Amrit's intellectual capability and the difficulty he had in making choices and voicing his opinions. He hoped that by introducing him to the idea of self-advocacy and by developing a portfolio Amrit would be able to express some of his feelings, define how he saw his situation and make some decisions about how to spend his time. Amrit was introduced to the thinking behind the project and, although he was doubtful about the use of a portfolio, indicated that there were areas he would like to explore for himself: his family, disability and religion. Kevin also felt that the total environment of the unit would enable him to reinforce and remind Amrit of the self-advocacy work in a practical way.

Dilemmas and resolutions

Kevin found himself facing the dilemmas posed by Amrit's extreme reticence. At first Amrit responded monosyllabically and made few unprompted contributions. Open-ended questions, challenges and lengthy silences did not seem effective in getting him to talk, nor did he respond to ice-breaking games or unfinished sentences. More directive questioning did seem to keep some conversational flow going but Kevin was aware that it meant he was setting the agenda, and he also felt as if he were interrogating Amrit. Amrit's reticence was not specific to these sessions and he himself was later to associate it with his feeling that he had nothing worthwhile to contribute. So the first dilemma Kevin faced was to find means of enabling Amrit to formulate and express ideas and emotions of his own without coercing him. Picking up on hints from Amrit, Kevin recorded the questions he was asking himself: 'Why does Amrit attach feelings to so little, to so few experiences – perhaps because he's scared of letting himself feel emotions?' Recognising this need of Amrit's to feel safe, Kevin at one stage allowed the sessions to develop along any lines that seemed to engage Amrit's full attention and caused him to speak with interest. Kevin wrote: 'Underneath some of these seemingly meaningless conversations, some important changes may well be taking place. However,

as a self-advocacy "tutor", if the student doesn't tell us about the changes taking place (which she or he is perfectly entitled to do) it is difficult to know how the sessions are going or where.'

Despite these anxieties about what, if anything, was happening, and where they were going, Kevin continued to offer Amrit this time and space each week. He hoped it was a way of giving Amrit permission, without creating any pressure, to explore areas that had previously been felt to be taboo. Finally, in month four of the project, a chance question about the weekend started a discussion of the videos Amrit had watched at home about Rama and Sita. This cycle of stories forms one of the central narratives of the Hindu sacred texts. Through this Amrit began to find ways of describing his values, and, very gradually, his feelings. He described himself as becoming 'more emotional'. Kevin encouraged this, in a non-threatening way, by using TV soap operas as an objective focus for discussing feelings and relationships without putting Amrit himself under the spotlight. Gradually the sessions became more structured again, taking as their starting point more personal issues from the previous one, or events during the week, such as the first time Amrit refused to comply with the wishes of a member of staff, and provided cogent reasons why. Amrit also identified his lack of a confidant, and Kevin realised that this was the first time in his life that Amrit had been able to talk about himself, feelings, values and relationships. By month six Kevin reported: '...the more we can talk about emotions/characteristics, etc., the more Amrit says it helps him to think things out.' Amrit chose, however, not to make a portfolio on the grounds that he would never leave the unit, never get a job and that he could get all the other benefits by working things out in his mind. Kevin was clear that a respect for the boundaries of privacy set by the learner is essential in this work, but that there will always remain some dilemmas about how far to push for these to be extended.

Tasks, skills and attitudes

The skills Kevin needed to implement the work with Amrit were akin to those required by a counsellor. Kevin was able to consult a counsellor working in education in order to acquire and develop his techniques, and to gain the support he needed for himself. Although Kevin's initial reservations had been about the risk of provoking intense and unmanageable distress, the actual worries were much more connected to feelings that Amrit did not want, or could not use, the time and attention that Kevin was offering. A feeling of being ineffectual, or of wasting time, can create a great deal of anxiety for professionals, so allowing learners to pace themselves requires a certain amount of faith and self-discipline as far as the worker is concerned. Kevin also saw Amrit daily on a different basis, but was conscious of trying to maintain the self-advocacy approach throughout the week. This all represented the use of a number of developing skills that were wholly informed by the worker's attitudes and personal qualities. In summary, this all involved:

- respecting the learner's reticence and wish for privacy;

- containing personal anxiety about outcomes;
- tolerating an often slow-moving and uneven process;
- varying approach and technique to suit the learner;
- maintaining strict confidence about personal revelations;
- non-judgmental acceptance of the learner's views and feelings;
- accepting the limits of his own knowledge about, and control over, the situation;
- dealing effectively with the feelings the process evoked in him;
- appreciating that cultural differences may make understanding and empathy more difficult.

Issues

- Counselling and guidance skills are not necessarily part of initial professional training, but are an essential component of self-advocacy work, and increasingly recognised as necessary in portfolio preparation in education.
- Strong arguments are often made against a professional taking on a counselling relationship when they already have an involvement with an individual in another way, since this may involve them in a conflict of roles. However, when professionals are committed to the promotion of self-advocacy in all aspects of their work, this role conflict may prove less problematic to both them and the learners.
- Professionals undertaking this sort of work stand in need of supervision to support them in maintaining boundaries and containing their own anxiety.
- There is a need for cross-cultural and anti-racist perspectives in counselling.
- Learners' views about the usefulness of portfolios need to be taken into account seriously, and their informed decision not to make one may represent a successful outcome.

Summary of key characteristics of successful work that arose from the project

Attitudes that promoted the work

1. A commitment to the right of disabled people to absolute parity of esteem with able-bodied people.

2. A belief in the potential of all learners, colleagues and parents for change and development.
3. A willingness to undertake personal development and self-reflection, especially in areas relating to disability, loss and bereavement.
4. An understanding that people draw their sense of themselves from how others respond to them and the ways in which society defines them. An expectation that changing the nature of the professional relationship with learners will produce a change in the learners' sense of themselves.
5. Resistance to becoming an apologist for the inadequacies of the provision available for disabled people.

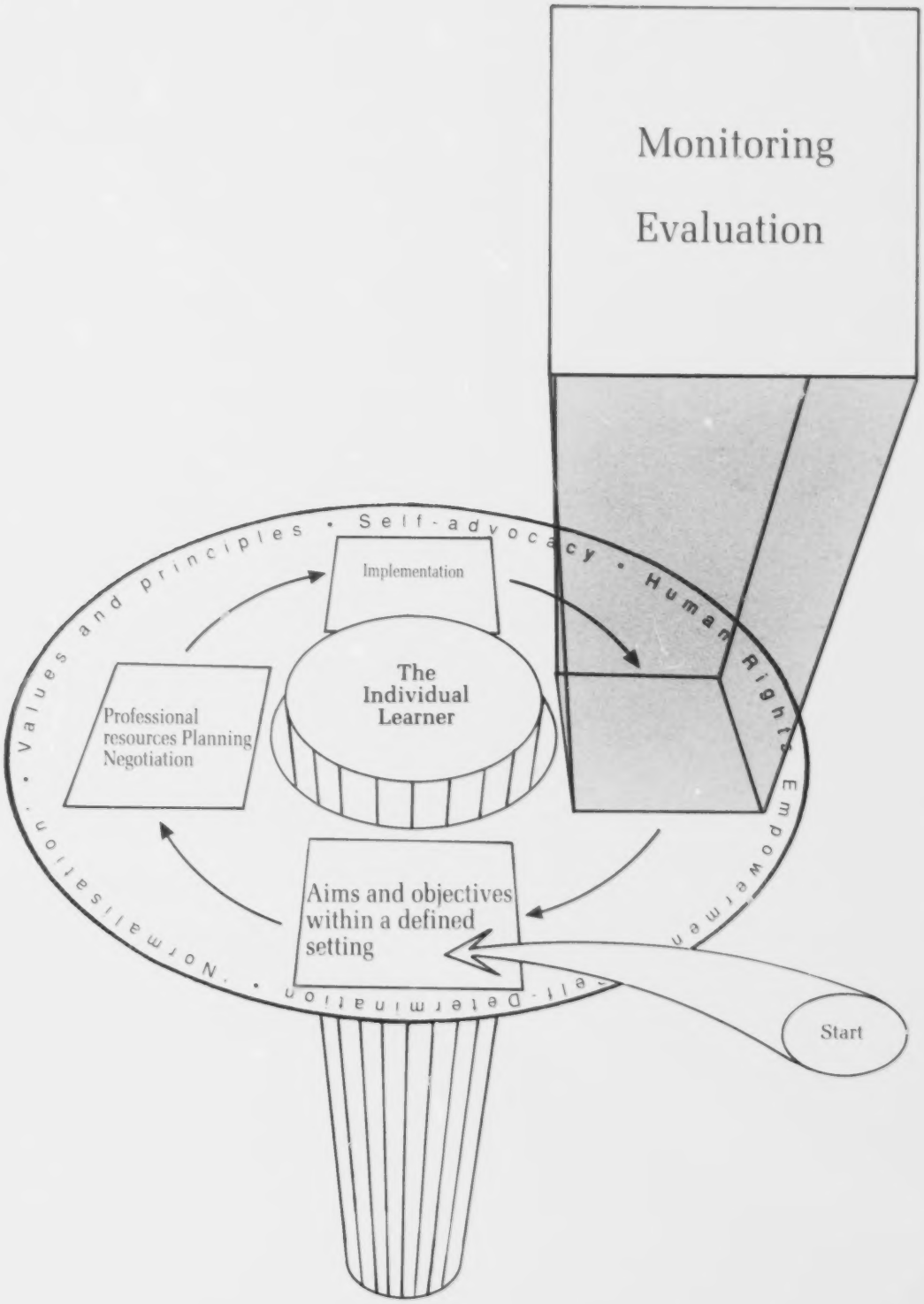
Skills and qualities that promoted the work

1. Liaison with parents, other agencies and professionals, and with potential employers. The ability to manage effectively.
2. The ability to motivate and stimulate the learners: games, exercises, quizzes, brainstorming, etc.
3. The ability to show resourcefulness in recording entries for portfolios: camera work, old photographs, acting as scribe, tape-recording, flowcharts, diagrams, etc.
4. The ability to use counselling skills.
5. The ability to be assertive and resolve conflict.
6. The ability to negotiate and develop trust.
7. The knowledge and understanding of key independence skills and of the job market.
8. The ability to plan for 'safe' risk taking.
9. The ability to address the learners' affective needs through relaxation, stress management, massage, etc.
10. The ability to implement effective assessment procedures and processes and to share these with learners.
11. The ability to engage in self-reflective learning and to demonstrate this through the keeping of effective records.
12. The ability to demonstrate patience and perseverance.

General issues that arose from the work

1. Differences between groups of different professionals in understanding and managing learners' mistakes and risk taking

2. The implications of empowering learners and for the responsibilities of professionals.
3. Issues connected with confidentiality and the requirements of different agencies that arise both for professionals and teachers and their families.
4. Possible conflicts of loyalty and responsibility.
5. The real availability of possible adult roles for the learners.
6. The different uses of portfolios when the emphasis could be either on the development **process** or the end **product**. This project was concerned primarily with a process.
7. The need for training in counselling skills for staff.
8. The need for professional supervision to be available for people undertaking this work.


Monitoring
Evaluation
Implementation
The Individual Learner
Professional resources Planning Negotiation
Aims and objectives within a defined setting
Start

Section 5. Monitoring and evaluation

Record keeping

The project gave great importance to the need for professionals to undertake consistent self-monitoring and to be supported in this by effective professional supervision. Although action research obviously calls for good record keeping, it is also essential in the development of professional practice and theory.

Outcomes are described in five areas. These are:

1. the movements towards adult status achieved by the learners;
2. the usefulness of portfolio preparation;
3. the professional development of the key workers;
4. a consideration of some themes that the project was unable to explore fully;
5. a check-list of the features of good practice.

First, however, the importance of record keeping to the essential task of monitoring practice is examined.

The Experiential Learning Cycle can provide a basis for a model of record-keeping; one in which the learners can share. For these purposes, its four stages can be interpreted as shown in the model offered in Table 4.

Most of the qualities given as the essence of experiential learning (Gibbs, 1988) are also a guide to what is needed in record keeping. These include:

- the active exploration of experience
- reflection on experience
- independence of thought
- openness to experience, with sufficient support for professionals to be able to evaluate what happens without fear of judgement

- an emphasis on the continuous nature of learning for both teacher and taught

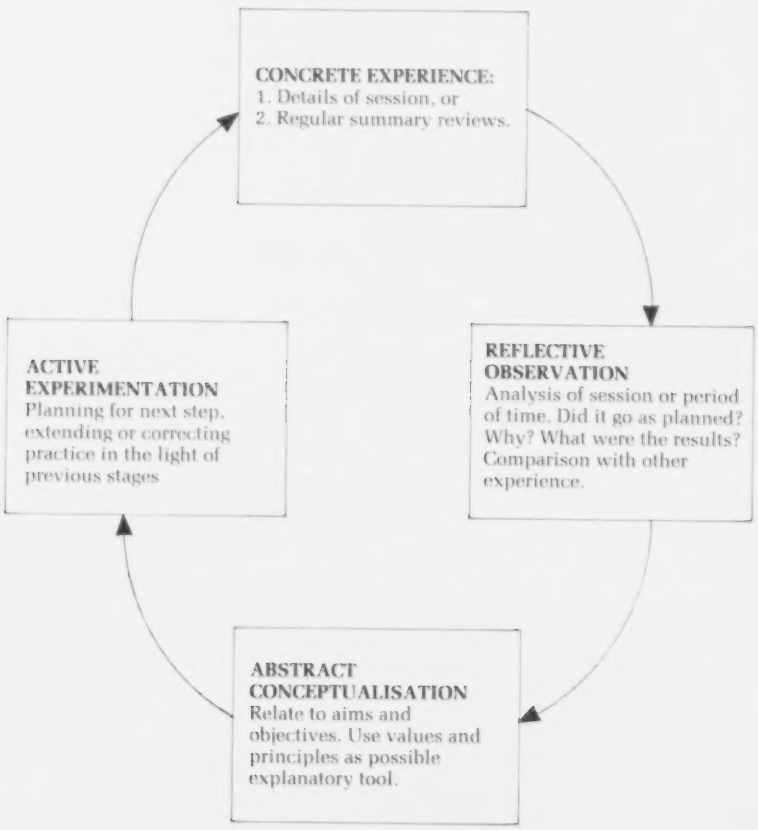
To these should be added:

- an attention to detail and accuracy, both helped by writing records as soon after the event as possible, if not as a conscious part of it

Through such record keeping it becomes possible to identify change and progress for both learners and professionals. Such changes are among the indicators of effective practice, and must form the basis of any evaluation process. This is not to imply that dramatic or spectacular changes are demanded. The ability to relate change to certain professional interventions is also important as is the understanding of a theoretical framework for the whole process.

Record keeping is, therefore, the basis for all effective monitoring of progress and subsequent evaluation.

Table 4. Model for record keeping


CONCRETE EXPERIENCE:
1. Details of session, or
2. Regular summary reviews.
REFLECTIVE OBSERVATION
Analysis of session or period of time. Did it go as planned? Why? What were the results? Comparison with other experience.
ABSTRACT CONCEPTUALISATION
Relate to aims and objectives. Use values and principles as possible explanatory tool.
ACTIVE EXPERIMENTATION
Planning for next step, extending or correcting practice in the light of previous stages

Transition towards adulthood

A fundamental principle of self-advocacy work is that all young people with disabilities have the same rights to adult status, and its various aspects, as other young people. This principle is then extended to adults who, because of institutionalisation, have been denied full adult status in our society.

Moving towards employment

At the start of the project none of the learners was in open employment and did not have expectations of being so. After eight months, the following had happened:

Of the learners in one-to-one situations:

- one had returned part-time to his previous employment;
- two people had had interviews for open employment, albeit unsuccessfully;
- one was in a work placement from a college course which offered him hope of a permanent job;
- another was looking forward to work experience which she had previously refused;
- another had had a successful interview for voluntary work.

Of the other four learners in this category:

- one was nearing retirement age;
- one had profound and multiple handicap;
- one had a shortened life expectancy;
- one was only just beginning the rehabilitation process after a gross physical trauma.

The two groups in the project both involved adults with learning difficulties, some quite severe. It was beyond the scope of the key workers to undertake the detailed support and negotiation needed to gain their entry into open employment. It may be that a self-advocacy group of physically disabled or sensorily impaired adults would have different results. Generally, the outcomes suggest:

- the key role of work in achieving independence and adult status;
- the high level of motivation that learners show when their goal of gaining employment is taken seriously or when it is presented to them as a realistic possibility;

- the importance of the attitudes and expectations of professionals in determining what learners feel are possible goals;
- the intensive level of professional support needed for preparation and during the first few months of employment;
- the limited number of options available for people with disabilities.

If disabled people are handicapped by the attitudes and assumptions of the able-bodied world, then a sustained attempt by able-bodied professionals to convey a different and opposite set of attitudes and assumptions should prove enabling.

Independent living

Independent living has also been identified as an important aspect of achieving adult status. There are many definitions of independent living, but the principles of **normalisation** identify some key areas:

- privacy
- freedom to come and go
- the right to visitors
- absence of regulations, e.g. compulsory bed time
- access to the kitchen and other areas at all times
- a space for personal furniture and belongings
- accommodation that is not marked out internally as an institution by, for example, standardised furnishings or decor
- accommodation that is externally indistinguishable from other domestic dwellings
- accommodation that is conveniently located, i.e., not in rural isolation

Although there is no theoretical reason why the parental home should not provide these conditions, in practice some parents might find it difficult to surrender that degree of control. Young people without disabilities solve these conflicts by leaving home, more or less amicably. For adults with disabilities, the difficulties this move away presents are often insuperable, and they remain trapped in a living environment which often reinforces their dependency and lack of adult status.

At the beginning of the project five of the ten learners in one-to-one learning situations were living at home with their parents, including one whose parents had given up their own home to move in with and care for him. At the end very little had changed for these five except that the one set of parents had managed to move out again. Otherwise, for two more of the five, there was no change at all; the fourth was waiting for building work to finish on a specialised housing project, and for the fifth the idea of

his leaving home was at least on the family agenda. Of the remaining five learners, two had moved from institutionalised and authoritarian regimes, one to his own flat and one to a rehabilitation ward which had established some normalisation principles; one continued to be cared for by his girlfriend; one remained in institutional care with a high level of need; and one continued to live in her own flat with support from social services.

In all, there were few changes in this area, although there were also some positive and encouraging developments, including Harry establishing himself in his local neighbourhood as well as in his own flat, Penny still determined to try independent living, and Stuart relishing the privacy and dignity of his new ward. One of the group members in the college-based self-assertiveness group was also evidently totally delighted by his move to a group house from a hospital setting.

The outcomes here suggest that:

- accommodation is an intractable problem for people with disabilities, with a great shortage of affordable housing which is also adapted to their needs;
- there is also an absence of the sort of flexible and appropriate support which would avoid putting the disabled person in a position of dependency;
- the paucity of provision makes it hard for young people with severe physical disabilities to think of leaving home, since their need for care has to be met somewhere;
- there is a real dilemma for professionals in encouraging disabled people to consider independent living when they know the inadequacy of provision. It is essential that learners are well-informed about their rights and equipped with the personal and political skills to campaign for them if they are to achieve the necessary support to live independent lives in the community.

Relationships with others

Adult status implies that a person is taken seriously. There were marked changes in the attitude of some parents, who began the long process of letting go of their adult children and recognising their capabilities as independent adults. Penny's parents had already decided to support her in leaving, but nevertheless found the process both difficult and protracted. Edward's parents watched him become independent in travelling to college and his work placement, and in beginning to establish a life for himself beyond the confines of the family. They also began to talk about how he might live independently of them. Val's family was shown that she was competent and enterprising in her job applications and her domestic abilities. In other situations the learners, through their portfolios and their demands on the system, began to be listened to and seen as adults with rights. Staff used Jonathan's portfolio as a topic of conversation and this

had positive effects on their other communications with him. Staff at the Social Education Centre were obliged to acknowledge People First and to meet their demands, although these also aroused some indignation and conflict. All such shifts in attitudes are not merely ends in themselves, but changes which should enable future personal development for the learners.

These outcomes suggest that:

- changes in professional attitudes, and particularly in giving attention and respect to the feelings and views of learners, have a 'snowball' effect, producing change in both the learners and in others who care for them;
- this snowball effect confirms the need for such change to be managed, and for professionals to communicate well with each other and with parents.

The concept of self-advocacy challenges the attitudes and behaviour of both disabled people and professionals. This project worked on the assumption that, if changes could be made in the relationship of professionals with learners, then a process of 'unlocking' the doors to self-determination and to adulthood could begin.

Knowledge of rights

The learners were continually reminded that they were entitled to certain rights, either moral, legal or specific to a particular institution. A number of learners insisted on their rights in large and small ways, effecting change and increasing their own self-esteem as they did so. Harry went to lobby his MP; Dawn exchanged a faulty sweat shirt; Penny campaigned against the closure of the computer workshop; and Stuart rejected the 'strict discipline' ward where he lived. It was also important that Edward was introduced to a member of the deaf community and began to understand himself as a member of a minority group with its own culture and language, who had a right to access to an interpreter on formal occasions. The People First group were able to send a representative to sit on the Local Planning and Development Team, and so exercise the right of people with learning difficulties to be represented in the planning of services for them.

The success of these learners in acting upon the knowledge of their own rights, once they had grasped it, provides some important lessons in devising the essential elements in the development of self-advocacy skills:

- professionals must be proactive in insisting that disabled people have rights, even to the extent of creating them in institutions where they do not exist;
- disabled people should be given clear information about their rights;
- the ability to represent yourself on public or political occasions and to know how to deal with those in authority is essential to self-advocacy.

These findings also vindicate the assumptions made at the outset of the project: self-advocacy is inextricably involved with the rights of disabled people, but rights have more than formal characteristics and effects. Knowing and acting to obtain your rights gains you more than the rights themselves, it also gives you a radically different view of yourself and your place in society.

Confidence and independence

A marked increase in the confidence of the learners was widely reported. Sometimes this came directly from the learners themselves, in remarks that show other kinds of perceptive thought:

'Some people think I don't know anything, but I can do lots.' (Stuart)

'Half of me feels more confident, and half of me doesn't.' (Val)

Key workers also commented upon the kinds of changes in learners that indicate increased self-confidence. For example, the self-assertiveness group became visibly more vociferous and communicative; a visitor commented on how well the People First group listened to each other; Amrit actually said 'no', and, what is more, to someone in authority; Dawn developed the confidence to initiate and close conversations. Such changes are not necessarily visible to the learners themselves; recognising such changes in themselves is itself a part of the process of establishing a sense of self-esteem. As Kevin reported: 'Amrit perceives only very slight changes in himself...yet everyone else he meets talks about the huge changes they see.'

The case-studies also show a substantial increase in the ability of the learners to begin taking some control over their lives through the setting of goals and making decisions. There is evidence of this in Val's determination to find employment; in Edward's rejecting his placement at the horticultural unit; in Harry and Penny both making use of campaigning techniques; and in Stuart's clarity in insisting that he wanted to continue with his sessions with Chris, even though his voluntary work — also his own choice — was taking up most of his week. In addition, the People First group were beginning to grasp how institutions and agencies made decisions, and were discovering how they could organise themselves in order to intervene.

Learners also developed some particular skills that were needed to achieve their goals. The exact nature of these skills depended on the nature of the goals, but the range included mobility skills; committee roles and procedures; letter writing; job interview techniques; publicising and setting up a voluntary club; domestic skills for independent living; and the ability to indicate choices from a range of options. All these achievements fed into the learners' sense of themselves and of their own self worth.

These outcomes clarify some theoretical understandings that were implicit but not clear at the beginning of the project. They concern the intricate

relationships between social position, relationships with others, self-esteem and the ability to acquire skills. Once professionals become committed to the entitlement of disabled people to certain rights, and recognise the validity of their point of view, they have already begun to question their own position as professionals whose job it is to 'know best'. This enables them to establish a different sort of relationship with their learners, based on a parity of esteem. Disabled learners are offered attention, are listened to properly and gain an increasing understanding of the rights, choices and goals open to them, as indeed do the professionals themselves. This affirmative relationship contradicts the many messages disabled people have heard about themselves and their abilities since birth, and helps to increase their self-confidence, their motivation, and, at best, their whole sense of what is possible. This, in turn, affects their ability to acquire skills.

The acquisition of skills is not simply a measurable, objective fact; it is an experience intimately related to an improvement in self-concept and self-worth. As skill acquisition feeds into self-confidence, the learners should become more capable of exercising their rights to self-advocacy, defining their own goals, challenging the barriers in their way and so achieving adult status.

The development of adult skills is vital in this process; they offer professionals and learners a 'way in' to more complex areas at the earlier stages of the work.

Portfolio preparation

Of the 11 case-studies, two involved work with groups and the other nine were based on work with either individuals or pairs of learners. As far as the portfolios are concerned, the outcomes of these two different types of case-study will be considered separately. Given the constraints of time and energy on the key workers, the group situations did not allow for the intensive work outside sessions that often took place in the individual work. The learners' limited literacy also constrained the ways in which portfolio preparation could be used within the groups. In individual work, key workers could support the literacy needs of learners by, for example, acting as amanuensis.

Individual portfolios

A sense of ownership

Portfolios should represent the owner in the way in which she or he wishes to be seen. This is also a goal of self-advocacy, and is particularly

significant for people with disabilities, who are often the object of 'expert' knowledge and definition by others. The extent to which the portfolio is successful in this respect can be judged by how far the learner appears to 'own' it, that is, to display attachment, pride and satisfaction with it and to be proactive in using it. Of the ten individual learners, Patrick, Jack, Dawn, Val, Edward and Stuart all displayed a strong sense of ownership. It is hard to speak of 'ownership' for Jonathan, the most profoundly and multiply disabled learner, although he evidently enjoyed the uses to which it was put by others. Harry remained highly ambiguous in his attitude, and although Penny seemed to tolerate hers, it seemed never to hold her imagination, and she omitted to take it to a job interview. Amrit's clear cut decision that there was no point for him in making a portfolio has already been discussed.

Uses

The learners who were most enthusiastic about their portfolios found the greatest number of ways of using them, but even those who were less absorbed in them as a product, benefited from some of the processes involved in their production, and also found some use for them.

The major uses were:

- Self-definition: this is part of the essential process of preparing portfolios. The contents of the portfolio became a visible testimony to the identity of the learner. The portfolios contained:
  - expressions of feeling;
  - accounts of the past;
  - records of positive relationships;
  - recognition of the learners' different social roles;
  - identification and evidence of skills and knowledge;
  - evidence of the learners' value to other people.
- Communication: the portfolios were also used as an aid or means to communication in more private settings. They were carried around, taken home, shown to peers and read and re-read, all with pride and pleasure.
- A personal resource: besides personal documentation, some portfolios became an information resource for their owners. They contained:
  - contact names and addresses
  - proforma letters for specific purposes
  - travel information, recipes, etc.
- Self-representation: this was a more purposeful activity in which the portfolios were used to present the learners' positive views of

themselves to other people in more public situations. The portfolios were used in interviews for:

— open employment

— voluntary work

— work experience

— case conferences, etc. within institutions

It should be added that there were favourable comments from other professionals who had reason to receive or review a portfolio. These included other members of a caring team, but also representatives of both commercial and sheltered employment. Ivor was able to seek the opinion of a small number of personnel managers, who all welcomed the idea of a portfolio being used at an initial interview. The reasons given included their wish to gain some idea of the personality of the interviewee; improved ease of communication; the portfolio itself as evidence of diligence and perseverance and the possibility of including concrete evidence of skills — for example, a sample of machining for textile workers.

The group portfolios

It is not really possible to generalise about the outcomes of portfolio production from these two groups. In the college-based group, all the members produced similar portfolios, and for the most able learner there may have been some sense of ownership. For the rest, the degree of learning difficulty made it difficult for them to recognise their own portfolio each week. However, the portfolios were presentable, professional, permanent records for the learners to keep. They enjoyed looking through them and having certain entries read back to them. Their greatest value was probably the opportunities they offered for structuring sessions, providing goals for activities, promoting a positive self-concept and providing an arena for the making of choices.

It was only towards the end of the project that the advisers to the People First group settled on alternating business meetings with additional skill-sharing sessions. Consequently, although the group members were enthusiastic about the idea, it was not easy to work portfolio preparation into the meetings, especially as there was a high level of difficulty with literacy. Despite this, a start was made with pictorial agendas and minutes, and members were encouraged to compile them into a folder. It is still the intention of the key workers to explore further the scope for portfolio preparation in this context. They anticipate a use for a group portfolio in applying for grants and in gathering material for campaigns on specific issues.

Portfolios as process

The experience of the key workers was that the processes of portfolio preparation were useful in developing self-advocacy skills. This was through:

- making the learner the centre of the sessions;
- giving the learner control over the portfolio entries, and the ways in which the learner was defined and his/her experiences recounted in them;
- providing a non-threatening focus for the work of affirming the learner;
- acting as a means by which issues connected to adult status could be raised;
- providing a permanent record of small acts of self-definition and choice.

In summary, the portfolios can be seen to have been a useful tool in developing self-advocacy skills. Their success was very clear for those learners who came to 'own' their portfolios, and to find definite uses for them as products. Even for those who were ambivalent or outright rejecting, the processes involved in portfolio preparation, and the opportunity to make decisions about their value, provided significant learning opportunities.

Section 6. The key workers

This section will look at the development in the professional practice and approaches of the key workers themselves, particularly as shown in their plans for the future. Despite finding developing self-advocacy skills every bit as difficult as they expected, all 11 key workers have firm plans to continue and extend it, and to draw upon the lessons they have learnt. They also all intend to integrate portfolio preparation into their future work, even those whose learners in this project were unenthusiastic or rejected it. The extent of their plans depends on the scope of their work remit and some of their intentions are outlined below.

Curriculum change in education

Having seen the effectiveness of a self-advocacy approach, there is a determination amongst the workers to ensure that it becomes a central tenet in both areas for which they are personally responsible and areas with implications for their department until, ultimately, elements should be included in all aspects of the curriculum. This is partly a matter of changing the approach of colleagues, but also includes planning explicit work on self-assertiveness, decision-making, and personal growth activities. The key workers also feel that portfolio preparation has much of value to offer, and intend to include it as a part of timetable activities. Despite its similarities to records of achievement, they see its somewhat different emphasis on learner-led content and its focus on affirmation as significant.

Staff development

Such changes in the curriculum imply a recognition of staff development needs. Where it is part of their remit, the key workers intend to include the principles of self-advocacy and portfolio preparation as central elements in both departmental and across-college training. They feel an important aspect of their own future development is to seek allies among colleagues and across other agencies. Where possible they will seek to find a basis for inter-agency staff development. At a practical level, there are intentions to use the training materials produced in the course of this project as a means

of sharing information with colleagues. The establishment of small resource banks of reference and teaching materials about self-advocacy and portfolio preparation is also envisaged.

Practice in social work and voluntary organisations

Key workers from social services or voluntary organisation settings feel greatly encouraged in their determination to facilitate self-advocacy in their contacts with clients. They also hope to develop the use of portfolios as a tool for clients in confidence building; as therapy; as a means to setting goals and to representing themselves; and as a resource for information. They anticipate using portfolios as a part of group work to promote clients' rights to representation within planning structures and to support clients in using such rights.

Job specification and selection procedures

The key workers all intend to explore the consequences of facilitating self-advocacy throughout their work and not just as an element to be confined to one slot in the timetable. They intend, where possible, to write the promotion of self-advocacy and portfolio preparation into the brief given to new staff members. They feel it is important to make plain during the appointment procedure that all members of staff will be committed to a self-advocacy approach for all learners. To this end they intend to find means of involving the learners themselves in the selection procedures for new members of staff.

New initiatives

The key workers see themselves as undertaking a number of initiatives as a result of their participation in the project. Some of these initiatives are novel developments, and they all represent an extension of the workers' professional roles and tasks. Some involve establishing new structures to ensure that the voices of learners with special needs are heard. These include establishing a Students' Forum with representatives from all courses for special needs learners, with an adviser from outside the FE College concerned; establishing a local People First group; and enabling learners to organise a self-advocacy conference. Other developments concern creating new forms of relationships. Among these can be included

the decision by a lecturer to work more on the wards of the mental handicap hospital where she is based, with both staff and residents, with a particular emphasis on self-advocacy and on portfolios for older people. Another worker has committed herself to taking on more of an advocacy role within another hospital for residents who cannot speak for themselves. There is also the intention to set up a parents' support group, and, within a different context, the proposal to negotiate with parents over learners' rights when their son/daughter is first admitted, and to ensure that the issue of the transition to adulthood is on everyone's agenda from the beginning.

Key workers also have important but more general intentions. As the work of the project has indicated, the fundamental attitudes of staff have a vital role to play. Key workers anticipate that they will be demanding additional resources, so that opportunities such as regular counselling can be made available to learners. They also see themselves as working towards client representation in all decision-making processes that concern them, and generally as trying to promote the rights of disabled people and the professional acceptance of these principles.

Key workers' self confidence

The key workers all reported an increased sense of confidence. They believe that this derived from an increase in knowledge about self-advocacy and portfolio preparation, and a greater understanding of the processes involved. They feel that the project made their philosophy more respectable and reputable, and confirmed that they had appropriate goals. In this respect, the project served the same function for them as portfolios did for the learners, by validating their experience and affirming them as individuals. Several felt that a greater appreciation of other perspectives, especially that of parents, had helped them to a wider understanding of the complex issues involved, and had increased their tolerance. Through this increased sense of themselves they felt less critical of, and less threatened by, parental reactions and so better able to respond positively. The key workers also drew reassurance from the fact that their work had stood the test of considerable scrutiny, and so felt greater confidence in their own capabilities and judgements. They recognised as well the value to their own development of the opportunity to reflect upon principles and to analyse their own practice in the company of like-minded peers. They were immensely encouraged by the similarities of their convictions across the substantial differences of professional background and institutional location to be found in the project.

Unexplored issues

During the project, a number of issues began to emerge which could not be fully explored. This section will briefly indicate these areas and raise associated concerns which might repay further research and consideration.

Sexuality

Key workers noted that issues connected to sexuality arose during their work, though not in any urgent form. They did not seem to require a particularly clear or decisive response. They indicate, however, a range of learner needs that may have become more apparent as trust developed over a longer period of time. Some of the incidents recorded are outlined below:

> Ivor and Isabel asked Edward straightforwardly whether he would like information about sexuality, conception and birth, and discovered that he had very little knowledge about any of these important areas. They therefore undertook a programme of direct teaching using the medium of BSL and the explicit material prepared by the Two Can Resources Unit. Information about AIDS and contraception was also given. Some of this was later reinforced by the adult member of the deaf community who was employed to introduce Edward to deaf culture.
>
> The theme of boyfriends was raised spontaneously by Val and Penny. In both instances the young women seemed to suggest that being able to attract an able-bodied boyfriend would solve all their other problems about employment and accommodation. On one occasion, the male members of the group, led by Debbie, added, of their own accord, the label 'married' to the list of self-descriptions that they found acceptable, although none of them was in this category. Debbie followed this up with a discussion of who the group members would like to live with, but felt that more detailed or intimate information was not appropriate at the time. It was less easy for her to deal with what seemed like inadvertent disclosure of sexual practices by one member of the group; with inappropriate suggestions from another; and with expressions of physical affection from a third.
>
> Frances faced a different sort of problem on Jonathan's ward where a male member of staff had introduced him to pinups from such soft pornographic magazines as *Mayfair* and *Playboy*, and had decorated his locker with images of naked women that she found offensive.

These incidents suggest a number of issues:

1. Some young disabled people, mainly but not exclusively those with learning difficulties, appear to have been denied essential information about sexual matters.
2. Lack of experience and of a peer group with which to exchange information may lead young disabled people to hold more than usually

unrealistic expectations about what a sexual relationship can and cannot offer.

3. Explicit teaching about the social significance of sexual behaviour and what is appropriate may be necessary in some circumstances if disabled people are to be seen as adult.

4. This whole area highlights the lack of privacy and the limited range of possible experimentation that is such a feature of the lives of disabled people.

5. There can be little doubt that the combinations of circumstances already described may make young disabled people, especially young women, particularly vulnerable to the sexually predatory person.

6. It was suggested by a number of professionals and other concerned people that note should be taken of the increasing recognition of the prevalence of the sexual abuse of children. Professionals working with disabled people need to be aware of the indicators of possible abuse, and to be prepared to recognise disclosures if they are made.

7. Disabled people have a right to good information, to their own sexuality, and to sexual expression, but it is an area where professionals need to be particularly careful about how they use their power to influence.

Counselling

The similarity of self-advocacy work and portfolio preparation to counselling has been remarked upon already. The key workers felt in general that they were often dealing with the residues of emotions that the learners had not had the chance to express, and which, until they could be directly dealt with, were acting as blocks to learning. Those working in a medical setting remarked on how often they had witnessed disabled people being treated in ways that denied them the right to normal human reactions. This was particularly acute in the two hospitals, where the residents' experiences of bereavement seemed to be handled largely through the mechanism of denial. This was literal in one instance where staff refused to give one long-term resident clear information about his mother's death, even though he was upset and bewildered because her regular visits had stopped. For people with learning difficulties, being denied such essential explanations is a heavy additional handicap. The British Psychological Society (1989) in its recent research also emphasises the widespread neglect of the emotional needs of disabled people, a finding confirmed by disabled people's own organisations.

All this suggests that anyone working with disabled people is likely to encounter situations that provoke strong negative emotions. Death and loss are acknowledged sources of distress and anxiety, and can be difficult to deal with. Society overvalues physical perfection, laying great emphasis on 'normality', and then ensures that those with disabilities face enormous

social disadvantages. The powerlessness of disabled people is not only a problem for those presently seen as being in that category, but exists as a threat to all those people who are currently assumed to be able-bodied. Any professional who has transformed their unconscious anxieties around disability into a sense of separateness from, or superiority to, disabled people is most unlikely to be successful at promoting self-advocacy skills. These considerations suggest that counselling skills have much to offer both disabled learners and the professionals who work with them. It might also be added that, although people with learning difficulties are often considered to be unable to benefit from such experiences, there is now some evidence to the contrary (Frankish, 1988; Kelley-Laine, 1988, pp47-9). The existence of non-verbal forms of self-discovery such as art-, dance- and music-therapy may also provide additional forms of resource.

Section 7. A check-list for practitioners

The project's key workers consistently emphasised that the most important component of developing self-advocacy skills was a professional commitment to the rights of disabled people to the same respect and opportunities for self-determination available to everyone else. They also appreciated that this needed to be translated into practice. Drawing upon their collective experience, they formulated, towards the end of the project, a list of specific issues that professionals must address if they intend to become involved in the development of self-advocacy. The check-list covers practical considerations, but also raises questions relating to principles and the ethos and culture of institutions.

Policy

1. Is there a written equal opportunities policy statement?
2. Is there a written commitment to self-advocacy?
3. Is there an assumption that the goals of and for disabled adults are the same as for the rest of society?

Resources

1. Are there timetabled opportunities to practise self-advocacy activities?
2. Is there a budget for learner-led activities?
3. Can learners undertake the administration of such a budget?
4. Are appropriate videos, teaching materials, information packs about self-advocacy available?
5. Are members of the disability movement or other self-advocates invited in on a regular basis to raise the awareness of learners and to act as role models?

Staff development

1. Is there in-service training about the principles and practice of self-advocacy?
2. Does training involve the participation of disabled people as trainers?
3. Is any training offered on a multi-agency basis?
4. Are there opportunities for staff to attend self-advocacy conferences as companions to disabled learners?
5. Are staff supported in obtaining further professional qualifications in associated fields, such as counselling or welfare rights, or in undertaking courses that lead to greater personal understanding and development?
6. Is information about new thinking and new developments routinely circulated to staff in a user-friendly way?

Support for staff

1. Are there regular staff or team meetings?
2. Does management offer active support to staff involved in the work?
3. Is there an induction period for new staff members?
4. Are team-building exercises regularly undertaken?
5. Is individual supervision timetabled into the work routine?
6. Is supervision available from experienced practitioners who have no direct managerial responsibility for the staff members concerned?
7. Can staff members learn from each other by team-teaching?
8. Are staff initiatives encouraged by management?
9. Are staff given recognition for any appropriate initiatives that they introduce?
10. Are individual members of staff allowed direct contact with outside agencies?
11. Are staff members offered guidance on their own professional and career development?

The environment

1. Is provision centrally placed or well integrated if it is part of an institution for non-disabled people?
2. If in a separate establishment, is it indistinguishable from provision for non-disabled people?
3. Is the environment attractive, open and welcoming to everyone?
4. Do the learners have some personal space?
5. Is there opportunity for privacy?
6. Is respect for the learners shown through all the arrangements, including, for example, sharing toilet facilities with staff?
7. If there is a space designated for only staff to work in? Do they spend as little time in there as possible?
8. Are the decor and furnishings attractive and adult?

Regulations

1. Are all the facilities readily available to learners?
2. Are the other facilities of the wider institution (if applicable) open to disabled learners on the same terms as everyone else?
3. Are learners introduced to issues about personal appearance and self-presentation and then given the same choices as other adult learners to have their hair and clothes the way they want?
4. Are learners free to move around?
5. Are the learners involved in drawing up any necessary regulations?

Sharing power

1. Is there an independent learners' committee or student council?
2. Are its officers/members elected by the other learners?
3. Does such a group manage its own budget?
4. If there is an adviser to the committee, is it an individual who is independent of the institution?
5. Does management act upon the recommendations of the committee?

6. Does the committee have direct contact with the service planners beyond their own department or institution?
7. Are there opportunities for learners to receive training in the tasks involved in running the institution?
8. Are learners represented on any management committees?
9. Are all records open to learners?
10. Do learners have access to the same information as staff?

Learner-centred programmes

1. Is there a defined induction programme?
2. Are all assessment procedures fully explained to the learners?
3. Are learners asked about their goals and needs?
4. Are the learners' initial opinions recorded?
5. Are all assessments written down, and are learners given a copy?
6. Are learners present at decision-making meetings?
7. Are all programmes based on individually identified needs?
8. Is there a written or agreed contract about such programmes?
9. Are such contracts regularly reviewed?
10. Is there a system by which the parents/carers can make their views known?

Negotiation and choice

1. Are learners always consulted about such basic matters as being touched, lifted or taken somewhere in their wheelchairs?
2. At the start of a session, do staff seek to gain the learners' consent to the content and methods of learning?
3. Is it acceptable for learners to say 'no'?
4. Is it accepted that learners may have legitimate criticisms of a member of staff?
5. Can programmes be changed at a learners' request?
6. Is there always a choice of activities within sessions?

7. Is there alternative provision if learners want to opt out of a session?
8. Are more experienced self-advocates brought in to raise learners' consciousness?
9. Do learners have access to the same information/records as staff?
10. Is one-to-one guidance and counselling available?
11. Are there staff guidelines about when to insist that a learner abides by a contract she or he has made?
12. Is there a policy on gaining learners' consent to behaviour modification programmes?
13. Where programmes are structured or highly directed is there staff guidance and discussion about how to manage the transition to more learner-directed methods?

Autonomy

1. Do learners organise their own events, e.g. fund-raising for charity, discos, etc.?
2. Do learners have the opportunity to handle and take responsibility for their own money?
3. Are relationships between learners fostered?
4. Do staff leave learners to resolve their conflicts without interference?
5. Are interpersonal skills fostered and taught?
6. Is there on offer a programme of sex education suitable for adults?
7. Are learners given the responsibility to get themselves to the right place at the right time with the right equipment?
8. Are learners encouraged to set the goals that actually meet their needs?
9. Do staff avoid channelling learners into what they know is available?
10. Do staff support learners in achieving their goals?

Risk taking

1. Do learners have the opportunity to learn to go out unaccompanied?
2. Are learners encouraged to go out alone once competent and safe?
3. Do learners use public facilities — buses, libraries, cinemas, sports halls, etc.?

4. Are learners allowed to use potentially dangerous equipment under the same health and safety regulations that apply to everyone else?
5. Is there an approved set of procedures for staff to follow when learners are exposed to risks, e.g. graded practice, close observation, consultation?
6. Are regulations so drawn up that staff can encourage learners to follow up spontaneous interests?
7. Has management considered its legal position in this matter?
8. Has management considered how to safeguard both learners and staff against the consequences of accidents?

Progression

1. Are there clear exit routes from the programme?
2. Are records kept of the destination of leavers to, e.g. jobs, training, day care, etc.?
3. Is there any long-term follow-up to judge the effectiveness of the programme?
4. Is there liaison with other agencies to avoid duplication?
5. Are there regular and timetabled self-assessments by learners?
6. Do staff record their own transitions from being directive, to sharing decisions, to putting the learner in charge?

Interagency work

1. Is there a local forum for exchange of information?
2. Is time for liaison work written into staff job descriptions?
3. Is there a staff member with designated responsibility for liaising with particular agencies, e.g. a job centre; local employers; housing associations; organisations of disabled people,etc.?
4. Has any aspect of the programme been modified in response to an approach by an external agency?
5. Are any collaborative projects undertaken?

Monitoring

1. Are learners involved in the systematic keeping of records?
2. Is record-keeping a routine feature of each session?
3. Are weekly summary reviews encouraged?
4. Are staff encouraged to develop a method of recording that is comfortable and effective?
5. Are staff given clear guidelines about what to include in their records?
6. Are there regular staff reviews to discuss overall objectives in the light of self-advocacy and to monitor progress towards these goals?
7. Are clear records kept of all initial assessments of learners, including their own self-assessments?
8. Are there records of all learners leaving the institution, with reasons, destination, and a final form of assessment from both learners and staff?
9. Are staff given the opportunity to reflect upon, and analyse, the records of their own practice in regular supervisions?
10. Are the views of learners about themselves, their progress and the institution sought and recorded?

Evaluation

1. Do the differences between the initial and final assessments by learners and staff indicate positive changes?
2. Do the destinations of leavers who have completed a programme suggest successful moves towards adult status?
3. Can staff and management give clear statements about their aims and objectives in terms of self-advocacy?
4. Can staff and management clearly explain how their methods and practice relate to self-advocacy?
5. Does the institution promulgate a theoretical understanding of how and why their practice is effective in promoting the goals of self-advocacy?
6. Is the institution open to evaluation and consultation by and with other interested people such as parents and carers, and disability organisations?

Appendix A. Aims and objectives of the project

Aims

1. To enable unemployed disabled adults to maximise their potential by making the most effective use of available support services through:
   a) the development of skills associated with self-advocacy and an exploration of the transfer of such skills;
   b) the development of personal portfolios to help ensure subsequent progression and a recording of the processes through which these portfolios have been developed;
   c) the examination of the criteria relevant to the composition of such portfolios and an exploration of the prospective target audience.
2. To promote staff development for professionals working with unemployed adults with special needs through a consideration of present and current work; a linking with agencies such as Skill: National Bureau for Students with Disabilities; involvement with the East Midlands REPLAN programme and with the UK contribution to the OECD/CERI project, RP 510; a national programme of dissemination (the FEU *Working Together?* series).
3. To provide support and staff development for key workers in the project.
4. To provide appropriate structures for support for parents and carers of individuals involved in developing personal portfolios, and to take into account the work being undertaken by the National Bureau for Children in connection with *Working Together?*, on supporting parents and carers of young people involved with self-advocacy.

Projected outcomes

1. A project report including details of:
   a) project implementation and evaluation;
   b) case-studies and personal portfolios;

c) implications for staff development.

2. A contribution to the programme of staff development activities organised by the East Midlands Regional REPLAN group.

3. A contribution to the OECD/CERI Disability Action Programme.

4. A programme of national dissemination.

Appendix B. The Steering Committee

From the outset the project officer was offered support in defining her brief by the Steering Committee, the FEU Officer concerned and the Project Consultant. Membership of the Steering Committee is given below:

Karen Babbidge, Divisional Education, Training and Employment Adviser, MENCAP

Mariette Clare, Project Officer

Deborah Cooper, Director of Skill

Kay Driver, REPLAN Field Office (until December 1988)

Dorothy Hemms, Derbyshire Centre for Integrated Living

Pat Hood, Development Officer, FEU

David Hutchinson, Work Orientation Unit, North Notts College of Further Education

Jean McGinty HMI

Christine Moore (Project Director), East Midlands Regional Curriculum Development Officer

Ian Pickering, Nottingham Advocacy Network

Terry Taylor (Chair), Head of Special Needs Division, Chesterfield College of Technology and Arts

Carol Tennyson (Project Consultant), Work Orientation Unit, North Notts. College of Further Education

Alison Wertheimer, Researcher and author of *Self-Advocacy and Parents: The Impact of Self-Advocacy on the Parents of Young People with Disabilities* in the *Working Together?* series

David Williams, Principle Assistant, Disabled Persons Division, Nottinghamshire Social Services

Thanks are also due to John Nieto of North London College, formerly of ILEA's FHE Curriculum Development Project, for his help. His knowledge

and experience in portfolio preparation was invaluable in assisting all the project workers to understand and explore what it offered them in developing self-advocacy skills.

Appendix C. Identifying the case-studies and key workers

A variety of considerations influenced both the way in which case-studies were sought and their final selection. Given the relatively short timescale, it was felt that key workers should already be interested, if not actually active, in self-advocacy, and aware of the issues involved. Taking part in the project would be a commitment to a substantial amount of extra work. Key workers needed to be not only willing but able to incorporate this into their existing commitments and programmes. They needed as well to be able to gain management approval for their attendance at project development days during working hours. Consequently it was decided to make a general trawl throughout the region, inviting prospective key workers to volunteer.

This initial process aroused considerable interest suggesting that the project was timely in consideration of issues around self-advocacy. For many professionals from differing backgrounds, developments of the last few years seem to have led inexorably to the conclusion that self-advocacy is an essential tool for disabled people. As a result of these contacts it was possible to select the 11 case-studies (rather than the six to eight originally envisaged). These were chosen to provide:

- representation across the five counties of the East Midlands;
- a balance of race and gender;
- a spread of types of disability – congenital, progressive and acquired – and a consequent range of associated educational and social handicaps. Sensory impairments as well as mental and physical conditions have all been included;
- a variety of professional backgrounds, including staff from health authorities and social services as well as education;
- different institutions and agencies, including a national voluntary organisation.

Appendix D. Self-organising associations of people with disabilities

Associations include:

Advocacy Alliance, 2 St Paul's Road, London N1 2QR

Asylum : A Magazine for Democratic Psychiatry, c/o Professor F A Jenner, Royal Hallamshire Hospital, Sheffield S10 2JF

British Council of Organisations of Disabled People, 071-267 6111

People First, c/o Kings Fund Centre, 126 Albert Street, London NW1 7NF

Survivors Speak Out (mental health), c/o Chesterfield Centre, Tontine Road, Chesterfield

Appendix E. Case-studies

Case-study A. Anne

Initial situation

Anne is an educational therapist who works in a rehabilitation unit for head-injured adults. The original contact with the project involved another FE lecturer who works there, an occupational therapist, and a social worker. They were all agreed that the social consequences of head injuries could be very far-reaching and that it is often difficult for individuals with this kind of experience to rebuild their lives. They felt that self-advocacy and portfolio preparation as concepts had much to offer. Anne was asked to undertake the project work since she was seen as committed to helping learners regain a sense of control over their own lives.

Approach

Anne works only with adults who express some educational need that she may be able to fulfil. These may often be the recovery of apparently lost skills of basic literacy and numeracy. Her first task is to build a relationship of trust and acceptance so she spends time talking about the problems caused by such things as loss of memory, loss of perceptual abilities, loss of mobility and physical dexterity and loss of easily understandable speech. She recognises that in the process of recovery, self-esteem plays an essential part and that this is further undermined by the difficulty in predicting the precise extent of the damage to the brain. Under these circumstances it is not easy for head-injured people to set goals for themselves, especially as they have to pull together a sense of their own integrity from before and after the traumatic injury. Much of Anne's work, therefore, is in clearing away some of the subjective barriers to learning which appear under such circumstances, and in providing the necessary motivation.

Reservations

Anne was concerned that portfolio preparation, with its emphasis on the recall of past experience, might not be appropriate for individuals with head injuries. She felt that remembering lost skills and achievements from

the past might unexpectedly confront learners with emotions too painful to handle. Neither did this intended focus on what has been lost and may not be recoverable seem likely to increase self-esteem and self-confidence. Although rebuilding a positive sense of identity is a crucial aspect of recovering from head injuries, Anne remained unsure for some time that portfolio preparation would be a useful tool. It was not until month four of the project, after she felt certain that she had gained the trust and confidence of the two learners, did she risk introducing it.

The learners

In month one Anne was only actively working with Jack at the rehabilitation centre, although she knew Patrick from visiting very ill patients on the hospital wards. Jack is in his early 20s and by this time had recovered well physically from the accident. However, he had been left with difficulties in perception and memory. He could no longer recognise places or common objects in unfamiliar surroundings or pick out significant features. Most difficult of all, he was unable to recognise faces, even of his own family. He also had lost any literacy skills he had ever had. His parents had given up their own home to help care for him. His ambition was to return to his old job, which was also the source of much of his previously very active social life, as a builder's labourer. It was very difficult for him to live with his inability even to travel independently, to be without the resources of a wage, and to have to depend on his parents and the (freely given) good will of his friends to enable him to have the clothes, spending money and holidays that were so much a part of his former lifestyle. Fortunately he had retained great personal resourcefulness.

Patrick had been much more severely injured physically, and, at the start of his direct involvement with the project in month four, was still using a wheelchair. A tracheotomy and considerable general difficulty with physical co-ordination also meant that his speech was not at all clear. Before the accident Patrick had been a psychiatric nurse and he made it plain that he did not appreciate the role of patient. He lived with his girl-friend who provided the, still extensive, care that he needed. His family of origin lived at a great distance but contributed to his determination to get better.

Outcomes

By the end of the project, Jack was back at work almost full-time, having acquired strategies for dealing with his perceptual losses, and was living alone once more. He had shown great pleasure and pride in his portfolio, and felt that it had helped him to recapture the sense of who he was.

Patrick was out of the wheelchair, and was on the way to physical recovery, although it was too soon to say what the final outcome might be. He had rejected much of what the rehabilitation unit had to offer,

preferring to rely on his own determination. His blunt self-advocacy was not always popular with the staff. He seemed to use the portfolio as a means to redefining who he was, and what he expected of himself and life. It was a private and personal document.

Case-study B. Bruce

Initial situation

Bruce is a community worker with a nursing background in mental health. He works for a unit managed by a social services department and funded through joint finance. This unit liaises with local hospitals, both for mental disability and for psychiatry, and works with residents on rehabilitation programmes that are designed to enable them to live in the community. Bruce, therefore, works on an individual or small-group basis with particular learners from the time they are identified as candidates for the programme, through the period of rehabilitation within the hospital, during their stay at a half-way house or similar institution, and on to their establishment in their own homes in the community. Once there, they will be supported indefinitely.

Approach

The unit is founded on the principles of normalisation, and is committed to re-enabling people to live free and dignified lives. Bruce understands that in his work it is inevitable that his role with regard to particular individuals will change as they progress along the route back to living in the community. At all stages, however, he tries to ensure that the learners are treated, as far as possible, as adults with equal power and status, and equal rights to understanding and respect. Bruce has also had the experience of feeling disempowered when confronted by the authoritative decisions made about residents by, for example, a consultant who may have less familiarity and contact with the person than Bruce himself.

Reservations

Bruce is very sensitive to the ways in which professionals, including himself, can deploy their power. He also recognises, from his own experience of working within them, just how powerful the hierarchies of medical institutions are, and how dependent residents have to become on pleasing staff in order to survive. Realising the degree of influence staff can exert, he feels some scepticism about how real learners' consent can be, especially in a situation where so much of their future depends on their

retaining the good opinion of staff. He has also, from practical experience, had to confront the questions of whose definition of adult competence should prevail. Especially in matters of life-style, patterns of saving and spending, standards of propriety and hospitality, and acceptance of what might be accounted domestic disorder, all vary greatly across and between social groups. Who, for example, is to say when or how often a given person should do the washing-up in order to be assessed as competent.

Bruce's hope is that self-advocacy, systematically encouraged, will help to correct these imbalances of power and that portfolio preparation might be a practical means through which disabled people could represent themselves at case conferences and reviews. Occasions which are routine and unimportant to professionals, may be of enormous significance to disabled people themselves, and intimidating to an almost unimaginable degree.

The learner

Harry is an ex-factory worker in his late fifties. He had spent much of the last decade in a psychiatric hospital during which time he had become highly institutionalised. When his involvement with the project started, he had already spent nearly a year on a rehabilitation programme, moving from a highly controlled regime to living in more normalised conditions in a 'half-way house' within the hospital grounds. There was no doubt that his one great aim in life was to leave the hospital and to return to the neighbouring town where he still had relatives living. In addition to all the other considerations, Harry had a physical condition which made him unfit for work.

Outcomes

By the end of the project Harry was well established in his own flat in his home town. He had reacquired the skills of domesticity and independent living and had begun to find an undemanding social network. Despite an initial interest, he did not find portfolio preparation useful or enjoyable.

Case-study C. Chris

Initial situation

Chris is an FE lecturer at a continuing education centre in a rural hospital for people with learning difficulties. It is expected that, in due course, the hospital will close down entirely, and there is a developing programme for resettling residents in the community. Nevertheless, a considerable number

of people will remain in the hospital's care for quite some time to come, particularly those who are felt to be less able or to have additional problems. The hospital is instituting individual programme planning and, during the period covered by this research, considerable reorganisation of some wards was taking place. Residents were being reallocated, regimes on the wards were being newly defined, and ward staff were being obliged to reapply for posts that carried new job descriptions. Although this all represented forward looking moves by management, it created considerable uncertainty for the staff, not all of whom were convinced by the philosophy behind the changes. It is part of Chris's work to liaise with ward staff, and she is included in IPP meetings and reviews when they concern learners with whom she has an involvement.

Approach

The continuing education centre has a very clear philosophy based on the principles of normalisation. All the programmes encourage communication skills and independence training for the learners. The centre offers professional training and development courses to staff from health authorities, social services and education, in self-advocacy and related areas of interest. Chris is committed to these approaches and is also adviser to the Students Council which promotes self-representation and decision-making among the student body.

Reservations

One of Chris's chief anxieties is that she feels that some members of the hospital staff do not share these principles, and that their perceptions of the learners differ from hers. She thinks that when the learners are seen as residents or patients, in a one-dimensional way, there is a tendency among staff to gloss over their rights to normal reactions and emotions, and to reduce any difficulties in behaviour or personality simply to the fact that they are people with learning difficulties. For example, she observed one learner whose grief at the death of his brother, his one remaining contact with his former home, was treated as a medical problem and 'solved' by a substantial increase in tranquilisers. She therefore felt some concern that learners' attempts to speak up for themselves would be neither encouraged nor welcomed, and might well be actively criticised on some wards.

The learners

David is in his mid-40s and has severe learning difficulties. He has spent most of his adult life in the hospital, and no longer has any family with whom to keep in touch. Due to the resettlement process, several of his friends had at this time left the hospital and he had lost contact with them. At the beginning of the project he had just begun an assessment process to determine what were suitable goals for his future. He was an enthusiastic

student at the continuing education centre, and it was planned to offer him courses to improve his skills in money management, his domestic and social skills, and to help him with his sometimes inappropriate behaviour. At the beginning of month three, Chris recorded an IPP meeting: 'The doctor said that David was not yet ready to leave the hospital.(...) There are no immediate plans for David to leave the hospital.' The following day the charge nurse on his ward informed her that David was moving to a residential high care hostel in the community for a week's trial, and if all went well he would not return to the hospital. This duly took place, and Chris lost all further contact with David.

Stuart is in his mid-twenties and has been in the hospital environment since his early teens when he was admitted to a unit for disturbed boys. His main behavioural disorder is that he is an obsessive collector of small items. Within the hospital he has acted as a postman for internal mail, and has functional literacy skills. He has a bus pass and can use public transport quite safely. He has also shown some entrepreneurial flair in purchasing cigarettes once out of the hospital, and then reselling them back inside at considerable profit. At the start of the project he lived on a ward which had a regime of 'strict discipline', which meant that he had no access to his own clothes or to the means to make snacks or hot drinks, and very little control over his daily routine. Every other weekend he visited his now elderly mother. Under these circumstances he had virtually no conception that he might lead a different sort of life.

Outcomes

At the end of the project, Stuart had been transferred to a ward which provided him with privacy, control over his environment and daily activities, and which was encouraging his rehabilitation for living in the community. He was also working four days a week as a volunteer at a charity that refurbishes and recycles old furniture. He had developed a portfolio in which he took great pride and through which he had come to identify what skills he had and which he still needed to acquire.

Case-study D. Debbie

Initial situation

Debbie is the Special Needs Co-ordinator for an FE college situated near a city centre. Besides having an across-college responsibility for all students with special educational needs, she is also in charge of an extensive programme for people with learning difficulties. Along with a hospital for this group, which is following a closure programme and where Debbie

used to be based, there are a number of day centres and different forms of community living available for people with learning difficulties. As part of the college programme targeted at this group, Debbie was offering a course in self-assertiveness. Despite interviewing students individually, she felt that most of them had been sent along by other professionals who identified the group members needing to improve their communication skills. As a result, she had a rather silent group with, in general, severe learning difficulties. Several of the learners use Makaton, and most showed very little ability to communicate with each other. Debbie's work was to a large extent limited to what she could offer them in one session a week. It was no part of her brief materially to change where they lived, their weekly programme, or their daily routine, although those were all topics for discussion. The choices and decisions of her learners were, therefore, in this context, about which topics to explore and what sort of activities to take part in.

Approach

Debbie's background is in social services and she is familiar with the principles of normalisation. She acts as adviser to the students committee at a large local day centre. She has also been active in the promotion of knowledge about self-advocacy among her staff and has run a self-advocacy development day.

Reservations

Debbie's chief concern was that her job description did not give her any brief to become involved in material changes in her learners' lives, except in so far as they concerned attendance at college. Her major query was, therefore, about the effectiveness of developing self-advocacy skills outside the context of other opportunities for change. Within the context of a college-based course, designed for people with severe learning difficulties, she anticipated that portfolio preparation would be useful as a tool or adjunct to the processes of developing communication and self-assertiveness skills, rather than as a product for another specific purpose.

The learners

This was a group of eight learners, four men and four women, all except one with severe learning difficulties. One of the men lived in supported independence in a group home and another moved to a similar situation from a hospital during the course of the project. Of the other group members, one lived in a hostel and the remaining five lived at home or in a family placement. This last situation concerned the youngest group member, in her early twenties, who was also by far the most able. It became evident that she had experienced a life of exceptional dislocation and loss, and expressed the view to Debbie that she had no-one she felt she could

talk to. None of the group had employment except through one of the two local centres which they attended.

At the beginning of the project most of the group members were reluctant to communicate, especially with each other, and appeared bewildered by being asked to choose. They could put forward few suggestions for activities to do, and seemed to have no opinions. Part of this, of course, could be attributed to the unfamiliarity of their surroundings and the newness of the relationship with the staff, although by month one of the project, they had already had five weeks in this situation.

Outcomes

At the end of the project it was evident that the group members were communicating much more freely with each other, and were able to express wishes and opinions. They had also begun to contribute ideas about avenues the group might explore together. The portfolios remained as permanent and attractive testimonies to the deliberations about the topics they had covered.

Case-study E. Elena

Initial situation

Elena is the development officer for a national voluntary organisation that offers support in the community for all people disadvantaged through having a moderate hearing difficulty. She works in a small industrial town which, with local pit closures, has an extremely high level of unemployment. She is able to work in close co-operation with the local FE college, with another well-known voluntary organisation and with local initiatives involving self-employment and training for unemployed or unwaged adults. Much of the organisation's work is with families and it also runs social clubs and a crèche. Elena has to be concerned with sources of funding, and her organisation has channeled much effort into devising training schemes to help unemployed adults with moderate learning difficulties gain access to the job market. Although her role is predominately organisational, she also has some involvement with individuals and with particular sessions.

Approach

Elena has a belief in the need for people with learning difficulties to know their own rights and to have the confidence to advocate their own

positions. The organisation for which she works clearly sees this group as disadvantaged. Elena's approach is essentially practical and she expects to see visible changes in the lifestyles and situations of the individuals with whom she works. She had already explicitly introduced some of them to the idea of self-advocacy. She felt it would be appropriate for her to work with an individual for one session a week to explore the usefulness of portfolio preparation to the adults with whom she worked.

Reservations

Both the development of self-advocacy skills and portfolio preparation seemed to fit well into Elena's orientation towards practical outcomes, especially as far as employment was concerned. Her major concern was that the research had an educational bias, and she felt that her background had not equipped her well for taking part in such an initiative. Her willingness to discuss these issues was a valuable contribution to the project and her self-doubt proved quite unnecessary. Her perception of the world of education, however, and her sense of intimidation are a salutary reminder to all professionals that to others they may well appear mysterious, out of reach and threatening.

The learner

Val is about 30 years old and lives at home with her parents and grandmother, neither of whom have experience of working outside the home. Her three sisters, both older and younger, have all left home having 'achieved' academic success, professional status and marriage. Val attended both special and mainstream schools and has functional literacy skills, but ten years within the protection of her home has not helped her self-confidence. Two years before the start of this project, she began the vocational course in catering run by Elena's organisation, and, having successfully completed it, returned to work on the Community Programme scheme in the canteen of a local centre that promotes self-employment among unwaged adults. Val is very keen to find employment for herself and dreams about having her own flat and even getting married.

Outcomes

Val is still living at home, but is perhaps seen in a more positive light by her family. She has had two job interviews which evoked favourable responses from those interviewing her, but has not to date been successful in finding a job. She has gained greatly in self-esteem and self-knowledge through the process of making a portfolio and it has been useful to her in her job hunting.

Case-study F. Frances

Initial situation

Frances is an FE lecturer who is employed by a college, but who is based in the continuing education centre of a rural mental handicap hospital. There is a closure plan for the hospital and many of the more able and less institutionalised residents have already moved out. Details of future plans for the relocation of residents are confidential to staff and involve little consultation with parents or concerned others, and none with the residents themselves. They also threaten staff with a great deal of upheaval and uncertainty about their own future. The staff, while not being uncaring, are under a great deal of pressure and operate within a hierarchical system of decision-making in which the residents are inevitably given little say. Many of those left are profoundly and multiply disabled.

Approach

Within the Continuing Education Centre there is a strong commitment to stimulating and developing to the full the potential of all students, however disabled they may be. There is a lively interest in promulgating the idea of self-advocacy for residents, and the centre has held self-advocacy days for both hospital residents and visiting people with learning difficulties. Frances is strongly committed to the fullest possible development of all the learners, whatever their degree of disability, and has a special interest in working with people with severe disabilities, and in establishing relationships with them that make advocacy possible. She feels, however, that this is running counter to the prevailing ethos of the hospital, where, on the wards, residents are rarely consulted and there is no planning of the sort that would offer and encourage systematic daily choices. Although the staff view themselves as allies of the residents and there is interest in establishing a local branch of Community and Mental Handicap (CMH) as the hospital closes, Frances considers that they do not examine their practice in the light of advocacy or normalisation principles. On one occasion there was a formal staff meeting on the changes entailed by the closure plans. It was held on a ward, in the presence of residents, who were ranged in front of the television set. Meanwhile the staff were gathered in another part of the room and holding a highly charged discussion. They seemed not to consider the possibility that while residents might not be able to follow the substance of the debate, that did not mean they were insensitive to the emotional atmosphere. Frances strongly favours an approach which assumes understanding and sensitivity in the learners, even if it is not manifested.

Reservations

Since her work is concerned with people with profound and multiple disabilities, Frances always raised the questions about whether and how self-advocacy and portfolio preparation could be adapted to fit their needs. She particularly questioned whether professionals could avoid, in some sense, imposing themselves, their values and their tasks on individuals with learning difficulties, especially those who might also have a sensory impairment and, in addition, lack speech and mobility.

The learner

Jonathan is in his mid-thirties and has been a resident in the hospital for people with learning difficulties since he was ten. Until that age he had been cared for by his parents who still visit him regularly and to whom he is clearly deeply attached. Jonathan's cerebral palsy also affects him physically and he is quadriplegic. He has some movement in one hand and can make his own signs for 'yes' and 'no', but he has no intelligible speech. In addition to this he has some unquantified degree of visual impairment.

Outcomes

During the course of the project there have been a variety of changes in Jonathan's life. It is increasingly certain that he will be moving out of the hospital as part of the closure plans, and Frances has indicated to his parents that they should consider what they would like to see for him, and has advised them to make their views known. A medical problem with his feet has also been attended to, and Jonathan can now, with help, support himself on them, and even manage a few steps. He has learnt how to choose from a list of offered options, and his portfolio seems to have improved the way in which other staff interact with him, giving them a way of perceiving him as an individual with his own interests and preferences.

Case-study G. Gayle

Initial situation

Gayle is a lecturer in an FE college in a good-sized town. The college has a well-established policy and programme for students with special educational needs. Gayle is a member of the special needs department, working mainly with young people with learning difficulties. She not only

teaches within the department, but liaises with other departments who also provide courses. The department also emphasises the importance of the learners getting out into the community and using as wide a range of available facilities as possible, from shops to outward bound courses. Gayle's work is organised in accordance with these values, but she was aware that developing self-advocacy would require her to adopt a different approach. The department has good links with local social services and special schools, so there is some inter-agency collaboration.

Approach

The philosophy of the department is to help all the learners to maximise their potential. Much of the work is structured along the lines of pre-vocational training and is underpinned by an understanding of the need for the learners to make a transition to adulthood. Attending college and being treated as a responsible adult is an important first step along this road.

Reservations

Gayle's major reservation was focused on the difficulty of changing her professional role within the unchanging institutional setting, especially in the eyes of learners who already knew her as a 'teacher'. She was particularly aware that learners were often dependent on staff and their opinions, having had little opportunity to develop a sense of their own autonomy. Gayle therefore feared that her own values and interests would inevitably bias the work she did and be an undue influence on the learners.

The learners

1. Althea

Gayle's first choice for promoting self-advocacy was with a young Afro-Caribbean woman, Althea, who was showing signs of emotional and behavioural distress. Gayle's timetable for the term was already fixed, but she was able to explain the project to Althea and to offer to meet her once a week. Althea was certainly interested in the ideas as Gayle presented them, and agreed to take part. Two meetings took place, during which it became clear that Althea felt very isolated in a predominantly white environment, and that she had behind her a history of sexual abuse and some unhappy experience with the Mental Health services. Gayle felt daunted by Althea's obviously urgent needs, and out of her depth in both the cultural and emotional areas. She felt that after having offered this attention to Althea, she could not withdraw it. At this point, Althea's pressing problems overwhelmed her and she ceased to attend college. Clearly, if she had continued, Gayle would have had to seek extensive advice and support

elsewhere and perhaps would also have had to find a means of referring Althea to other provision, without making her feel rejected.

2. Dawn

Dawn is a young woman of twenty-six with moderate learning difficulties, and the loss of vision in one eye. She had been to a special school, and had spent some time at a local day centre for people with learning difficulties. As a teenager, she had been taken into care by social services, and now lives alone in her own flat, with social work support from two key workers. She is also cared for by a foster family with whom she spends the bank holidays. Dawn manages the practical aspects of her life excellently, but has no close friends her own age. She seems very dependent on professional support for companionship. At college she is diffident and shows little confidence in expressing her own views. She and Gayle arranged to meet once a week, although the exact time and place of each meeting sometimes had to be renegotiated. At the beginning of the project she was in the first of a two-year programme at the college, following courses in basic education, as well as catering, and beauty and health.

Outcomes

At the end of the project there had been no dramatic changes in Dawn's lifestyle. She appeared to have gained in self-confidence and social skills, being able, for example, to open and sustain a conversation, and to disengage from it when she was ready. In addition, she was now eager to try out a work placement in the following academic year having previously been most reluctant about the prospect. She had also, with Gayle's encouragement, extended the range of social facilities that she used. This in turn, by widening her experience and social contacts, was increasing her confidence and improving her ability to get on with people. This in itself is one of the key requirements for being able to hold down a job, and for being seen as acceptable in the employment market. Although she was always amenable to preparing material for her portfolio, it was some time before she began to assume a sense of ownership, and to value and appreciate her own abilities that were displayed within it. Gayle is intending to continue work on self-advocacy skills in the next academic year on a more securely timetabled basis, and Dawn will be able to be a part of this ongoing group.

Case-study H. Harriet

Initial situation

Harriet is a day-care officer in her early 20s in a newly opened Resource Centre for disabled people in a small, rural town. Other community groups are encouraged to use the facilities of the Centre on the understanding that they will involve Centre members in their activities. As the project started, Fieldview had yet to open its doors to its members and was in the process of developing its philosophy and guidelines for practice, and in building a working team from the newly appointed staff. Several members of staff were interested in taking part in the project as their intention is to build self-determination into the Centre's methods, and to enable members to develop programmes for themselves which take them, where possible, out of the Centre and into generally available facilities. Of those interested, the lot fell to Harriet to take part.

Approach

The entry of the first group of disabled users into the Centre coincided with month two of the project, with the second group not expected until month five. Harriet therefore anticipated having enough time to establish portfolio preparation before she had took on the responsibility of additional Centre members. As the description of Fieldview suggests, the principles of normalisation and self-advocacy are at its heart. What Harriet hoped to gain from the project was knowledge of using portfolios to attain these ends.

The learners

Penny is 26 years old and lives at home with her parents, her brother and sister both having established independent lives. After leaving special school, she spent two years at a residential college for young disabled people and then seven years at a day centre. Penny has cerebral palsy, uses a wheelchair and will always have substantial needs for help with personal and domestic care. Prior to the start of the project, she had begun to attend a professional computer training workshop, Brook Vale, run by a national voluntary organisation. This organisation also provides purpose-built or especially adapted houses for people with severe physical handicaps, so that they can live independently, supported by the necessary degree of personal and physical care. Penny has also decided to leave home in order to live in one of these shared houses with two other young disabled women, and to try to establish an independent life for herself. Penny therefore had real decisions to make and goals to set for herself. To Harriet,

portfolio preparation seemed to have a useful, if subordinate, role in this process. In many respects, Penny's situation appeared to suit the original intentions of portfolio preparation. She had no formal qualifications although she is clearly intelligent and articulate. The process of preparing a portfolio would therefore enable her to identify the skills and knowledge she had acquired, and the finished product could be used to help her present herself to others. Harriet was able, initially, to spend several sessions a week with Penny, on a variety of activities, although this time commitment was expected to taper off after the first three months.

Outcomes

At the end of the project, Penny was still waiting to make the move into her new, independent home. She had had one interview for a job, although without success. This was not an easy time for her, and much of her emotional energy during this period had gone into anticipating the house move, and into contesting the closure of the computer workshop. She had put together a portfolio, but it had never really become a vehicle for exploring either her capabilities or the possibilities for the future. Despite this apparent lack of success of portfolio preparation with Penny, Harriet began to use it with another member of the Centre, for whom it seems to have considerable potential.

Case-study I. Ivor and Isabel

Initial situation

Isabel is a social work assistant in a specialist team serving the needs of deaf people across a number of small towns. The team is strongly oriented towards the rights of deaf people, especially their right to an interpreter, and promotes as well the value of deaf culture. It is obviously part of Isabel's remit to work in the community with individuals and their families.

Ivor is lecturer in charge of deaf students at an FE college with an extensive programme for disabled young people and a strong commitment to work experience and employment. His brief is to support hearing-impaired students across the college and in work experience and to act as a resource for other staff members. He also maintains close links with the Social Services Team for Deaf People and other agencies and institutions of deaf culture.

Approach

Both key workers are very committed to the promotion of deaf culture, which encapsulates, of course, the self-definition and self-representation of deaf people. Through being part of deaf culture and through using British Sign Language (BSL), individuals can become part of a milieu in which they are not disabled, nor labelled and stigmatized as such. Deaf culture also provides a means for self-organisation, and a position of strength from which negotiations with the hearing majority culture can take place. It follows from this that both Ivor and Isabel see many deaf people as having been denied the opportunities, and the tools to make the most of them,that they deserve. In particular, Isabel would identify the emphasis on oralcy and the denial of BSL to deaf children as an infringement of their human rights to a language. They see the whole concept of self-advocacy as an extension of these concerns, and portfolios as potentially a very useful aid to communication with the hearing world, as well as a means of self presentation.

Reservations

The main reservation felt by Isabel and Ivor concerned the potential impact on the learners' parents of the consequences of encouraging self-advocacy. The role of parents in the lives of disabled people is discussed at length elsewhere. It was clear to these key workers, perhaps especially to Isabel who worked directly with families, that determined change for the disabled person could cause considerable disruption to the finely balanced equilibrium in some households.

The learners

Edward is 20 years of age and profoundly and pre-lingually deaf. He is also mildly affected by cerebral palsy which causes a certain lack of dexterity. He lives at home with his mother, who is confined to a wheelchair with severe arthritis, and his father who has been long-term unemployed. He attended a special school for deaf children. By the age of ten he had been labelled an oral failure, and indeed he still has virtually no useful speech. So it was not until his very early teens that he was introduced to BSL. After leaving school, he had an unsuccessful period of attendance at a different FE college from the one where Ivor teaches, and now attends a Horticultural Unit for adults with learning difficulties. This placement takes him to the FE college once a week, which is where he met Ivor. Although 20 years old, he never leaves the family home alone, except to visit his married sister or grandparents who live very close by. Ivor feels that Edward has a great deal of unfulfilled potential, and undertakes to meet him, with Isabel, for a weekly session of two hours. Isabel is already involved with the family, and together they make three-weekly visits to Edward's mother. In addition, they both spend additional time in arranging contacts with other agencies and institutions.

Outcomes

By the end of the project Edward had left his placement at the Horticultural Unit and had begun to attend college. He had clearly defined goals for his future, and was some way towards meeting them. He had coped with work experience, and could shop and use the public transport system with confidence. At home he was in charge of his own personal care, and the question of his ultimate independence was on the family agenda. He had been introduced to members of the deaf community, and had improved his grasp of BSL, along with general literacy and numeracy skills. He also demonstrated that he knew his own rights and was prepared to act to gain them. He showed enormous pride and pleasure in his portfolio, and used it effectively in both public and private situations. The increase in his self esteem and in his ability to shape and control his own life was remarkable. It has also to be noted, however, that this case-study involved a high degree of inter-agency co-operation, included work with the learner's family, and took rather more than two hours a week of each professional's time.

Case-study J. Jane and Jenny

Initial situation

Jane, an experienced social worker, is a member of a Community Mental Handicap Team which also includes nurses and residential and day care staff. In month three of the project, she unfortunately became absent on three months sick leave. During this period her place was taken by Jenny, an occupational therapist from the same team. On Jane's return, they continued to work together. Previous to any involvement with the project, Jane had taken two people with learning difficulties from the small city where she works, to a People First Conference in London. The result of this initiative was the setting up of a local People First group, made up of people attending the city day centre. The group meets in a building run by an educational voluntary organisation in order to highlight its independence from the Centre. Although Jane and Jenny belong to the same team, they are not on the staff of the Day Centre and are therefore able to act as independent advisers to the group. In this case-study, therefore, self-advocacy was already familiar to the learners.

Much of the work of the Community Mental Handicap Team has been taken up with the relocation and resettlement of ex-hospital residents in the community. With the completion of the hospital closure programme, a period of change and expansion was drawing to a close. Both Jane and Jenny felt that options open to people with learning difficulties were

closing down, and that availability of suitable accommodation was a particular problem.

Approach

Both Jane and Jenny felt a deep commitment to self-advocacy, and welcomed the opportunity to extend their professional skills into portfolio preparation. They had already undertaken something similar with a group of older people, using autobiographies and reminiscence work to help them say how they would like to spend their time. They also felt a little unsupported in their championing of adult roles for people with learning difficulties. In their perception, the views and capabilities of the group members are not taken seriously by Day Centre staff. In one incident, the group members organised a Day Conference for other people with learning difficulties. They had successfully undertaken many of the tasks this involved and the day went well. Unfortunately, they had forgotten to cancel their lunches at the Day Centre. This led to some conflict between Jane and Day Centre staff, who had certainly had the inconvenience of sorting out a large number of uneaten lunches. The way the issue was raised was by the Day Centre staff querying whether the group members were 'ready' for self-advocacy.

Reservations

Such experiences as the one described above caused Jane and Jenny to worry about how far self-advocacy creates new difficulties for people with learning difficulties. They had no doubts about the need to improve available options, and identified many ways in which individuals were treated without respect and denied of adult roles. However, they also saw quite graphically how the first moves toward self-assertion and self-determination could be derided and blocked. These questions therefore were about how to convince other staff that a change of attitude would allow them to see mistakes and 'stroppiness' as positive and unavoidable stages in self-development.

The learners

The People First group had a core membership of six-eight people and several other individuals attended at different times. The group members had very limited literacy skills and some members had difficulty with communicating. Their enthusiasm for their group was, however, transparent and there was never a shortage of volunteers for various tasks. With the guidance of the advisers, all members were encouraged to participate and women were enabled to take on official jobs.

Outcomes

Despite a disrupted year, with Jane's absence and building work at their Day Centre resulting in loss of their transport to their meeting place, the group continued to develop. They asserted their right to attend, and made their own way there, at one time pushing a physically disabled member in his wheelchair. By the end of the year, they had learnt to deal efficiently with the 'housekeeping' aspects of their meetings, were working on the more formal side of group organisation and had made and distributed membership cards. They were planning another conference for people with learning difficulties, had joined National People First and were sending a representative to the local social services planning and development group. Through the help of their advisers, and because the advocacy group made the need plain to them, they were also working on alternate weeks on some basic literacy and life-skills. At least one of the members demonstrated communicative abilities and a willingness to participate that Jane and Jenny had not observed in him anywhere else. The group working skills of the members in listening to each other, speaking in turn, and so on, had also markedly improved. With these general developments, the use of portfolio preparation has still to be tried out. From the work accomplished during the period of this project no definite conclusions were reached, but it seems possible that the concept of portfolios may well prove useful to the group in an adapted form.

Case-study K. Kevin

Initial situation

Kevin is the lecturer in charge of an FE unit for students who are so severely disabled as to be unable to attend a mainstream college. All are in wheelchairs and about half have a shortened life expectancy. They can attend for a period up to three years. Since it is a small unit, the learners and staff all know each other very well and each learner follows an individualised programme. The unit also acts as a reference point for information about electronic aids and information technology for disabled people. It is a self-contained unit, but it is situated some way out of the city centre in the grounds of a special school for children with physical disabilities.

Approach

The philosophy of the unit is that educational provision for this group of young people must take into account the learners' needs to look at

themselves, their past, their expectations and their fears. Kevin characterised the learners' needs as being for relationship, meaning, contentment and moral or spiritual answers. Without being addressed, these urgent needs can only create blocks to learning in a more conventional sense. Young people in this situation also seem to the unit staff to have internalised oppressive feelings of worthlessness, and to experience not only a lack of a variety of roles in their own lives, but also to have no positive role models to follow. There is a students' council and, as far as possible, the unit is run through consultation and discussion. Self-advocacy therefore fits well into this pattern of working, and portfolio preparation seemed to offer a useful additional tool.

Reservations

Kevin's reservations stemmed from two main concerns. The first is the issues raised by the fact of shortened life expectancy. Although the learners may know the name of their condition, they often do not appear to have been given clear information about their prognosis. Neither Kevin nor his staff had directly received any training in bereavement counselling and he was aware of this lack of expertise, and anxious about 'taking the lid off'. The second reservation was connected to parents and their parallel lack of information and understanding. If the Unit operated a 'right to know' policy for the learners, this would obviously affect the parents. Additionally, the parents themselves are clearly facing one of the most difficult experiences to deal with: the death of their child. Kevin was aware that they adopted a variety of strategies to deal with this, and he feared that changes wrought by promoting self-advocacy for the young people might radically destabilise an already fraught home situation.

The learners

Amrit celebrated his 21st birthday during the course of this project. He has Duchenne's muscular dystrophy. He lives at home with his parents, who are from India, and his two sisters. His Hinduism is an important feature of his life at home, and he has made a visit to India, which was also in part a religious pilgrimage. He is of very high academic ability, having completed an Open University course in mathematics. Amrit is very determined to accomplish as much for himself as he can, but it is now very arduous for him to use even an adapted electronic keyboard.

The effects of the disease began to show when Amrit was still at primary school. By the first years of his secondary education, he was in a wheelchair and attending a special school. In his mid-teens, he spent a period of over a year as an elective mute, speaking to no one. He is still sparing of his speech. At the beginning of the project Kevin decided to spend about one-and-a-half hours a week with Amrit, specifically on self-advocacy skills, but he recognised the value of being in daily contact with him and of being able to raise the pertinent issues within a variety of contexts.

Outcomes

By the end of the project, Amrit was in possession of a great deal more information about his condition, and had started to air and discuss thoughts and feelings that he had never previously disclosed. The staff at the unit, and others who came into contact with him, commented on the remarkable increase in his willingness to express himself and to make his opinions known. He himself said that he previously felt that nothing he had to offer would be of value. Although there was no change in his lifestyle, within those constraints Amrit seemed to feel more in control of his life, being more outgoing and good humoured. He was definite that he did not want to produce an actual portfolio since he believed that he would never leave the unit or look for work, but he did enjoy some of the processes that go into making a portfolio. These included gathering more information about his muscular dystrophy, defining himself through reflecting on his experience, and examining the values which he holds.

Appendix F. Sample portfolios

These three portfolios represent a sample of the work undertaken by the project. They derive from the case-studies. but all attempts have been made to preserve confidentiality . They are:

Portfolio 1. Patrick : Case-study A

PATRICK THE HOLIDAYMAKER

Tenerife

A tan is important to me because I look good and feel good and that is psycho.logically good! That's a fact Jack!

I'm going to Greece for a month in September with Barbara.

The real Patrick living!

A party in the nurses home.

SPORTS

I've won two winners medals for football

- 1 for school

- 1 for Youth Club

LOADSA medals for running.

5th in all Ireland championships - 2 miles.

Gymnastics team

I WAS VERY FIT

I'm a blue belt in Tai Jutsu.

My Auntie and My Mum at Knock Shrine in County Mayo.

Question: Is there anything you want to say about your Mum?

Answer: Just that I love her very much.

MY DAD

He's small with a big heart.

He's been round the world loads and loads of times.

He was in the merchant navy.

He's where I got my want to travel from.

PATRICK

WHO AM I - WORKSHEET

I ..am..NOW.....A...WALKER.....

I ..feel....PARTLY...TIGHT.....

I ..can....WALK.....

I ..like....SWIMMING.....

I ..think....TO..TRAVEL..AWAY..TO..SEE..WORLD..AGAIN...

I ...need...FOOD.....

I ....DRINK.....

I ....WANT....TO'S..TO..TRAVEL.....

I ....WISH....A..COMPANION.....

I ....NEED....MONEY.....

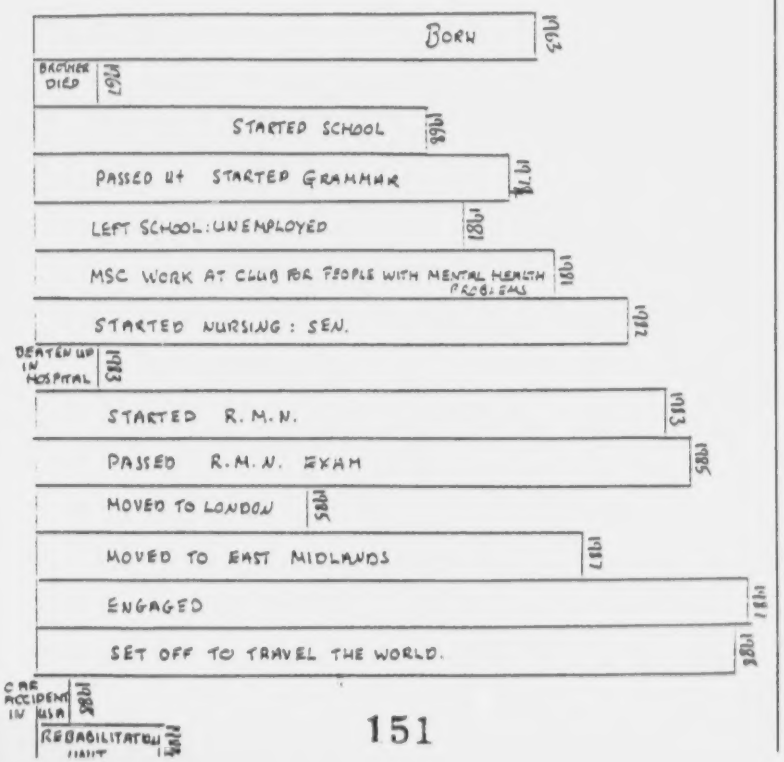
I UNDERSTAND I WANT TO GO

I HATE SCHOOL

I BELIEVE THAT I AM GOOD TOWALK AGAIN + TALK.

LIFE'S HIGHS AND LOWS.

Patrick.


BORN 1963
BROTHER DIED 1967
STARTED SCHOOL 1968
PASSED 11+ STARTED GRAMMAR 1974
LEFT SCHOOL: UNEMPLOYED 1981
MSC WORK AT CLUB FOR PEOPLE WITH MENTAL HEALTH PROBLEMS 1981
STARTED NURSING: SEN. 1982
BEATEN UP IN HOSPITAL 1983
STARTED R.M.N. 1983
PASSED R.M.N. EXAM 1985
MOVED TO LONDON 1985
MOVED TO EAST MIDLANDS 1987
ENGAGED 1987
SET OFF TO TRAVEL THE WORLD. 1988
CAR ACCIDENT IN USA 1988
REHABILITATION UNIT 1989

SKILLS I HAVE	PATRICK	
Used sign language		
Cooked a gourmet meal	✓	
Used a statistical method to solve a problem	✓	
Participated in the mass production of a product		
Written an essay	✓	
Read about British history	✓	
Studied a religion other than your own		
Read at least one newspaper and one magazine regularly		
Operated an office machine		
Judged the impact of television on children		
Gained understanding of major periods in the development of an art form, such as music, art or literature	✓	
Learned how one or more cultural or political systems evolved	✓	
Learned how one or more cultural or political systems evolved		
Exercised regularly		
Delegated responsibility to others	✓	
Applied for a grant or loan	✓	
Decorated a home or office	✓	
Been interviewed for a job	✓	
Used mathematics to solve a problem	✓	
Campaigned for a political candidate in an election		
Worked to a budget	✓	
Visited a foreign country	✓	
Read extensively about a historical era, event or personality	✓	

© APEL PACK, ILEA

61 Elms Avenue
A City

Dear Anne

Thank you for your letter concerning Patrick, we would be delighted to contribute to Patrick's portfolio.

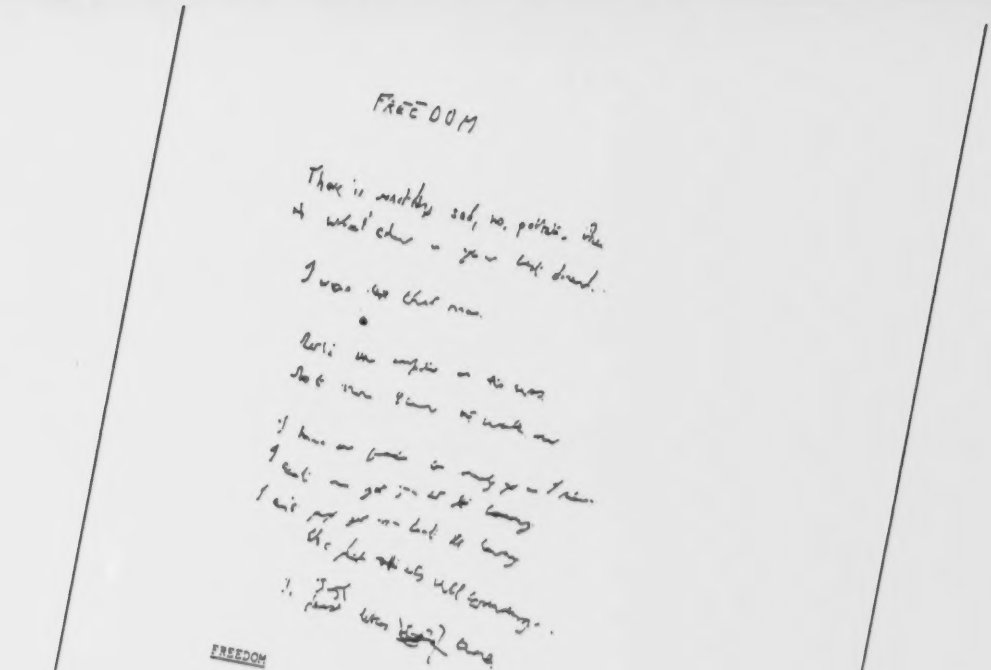
We deeply appreciate all the hard work, encouragement and inspiration given to Patrick by all the staff of the rehabilitation unit.

It has been most difficult for us as a family not to participate in this but we respected Patrick's decision to remain in the East Midlands to complete his rehabilitation, loving him and knowing his reasons. The most admirable quality Patrick has is his total belief in himself and his capabilities. Patrick's slogan is 'Go for it', 'Live on the edge'. He has applied this most of his life, at times charging in where angels feared to tread.

He is fiercely independent but underneath this has always been the desire to be loved, admired and most important, to be needed. He hides his tenderness from those close to him but shares it whole-heartedly with those in need of it most, for example, in his profession as a psychiatric nurse. We all have a great love and pride in Patrick, we feel his weakness, his vulnerability, his anger and his impatience with his situation, but knowing him as we do he will overcome his drawbacks and regard this as just another challenge. Then we will have our big headed, conceited, exasperating loving son back again.

Well Anne, have I helped in anyway? I hope I have. I am looking forward to Patrick's visit, we all are. We miss him so and my arms ache to hold him close at all times but he is a man now, and not the little boy who needed his Mum to kiss away the pain. Give him a big hug from me.

David and Theresa O'Toole



FREEDOM

There is something sad, no, pathetic, when
A wheelchair is your best friend.

I was that man.

Note the emphasis on the was.
Not now, I can walk now.

I have the freedom to nearly go as I please.
I can't run yet, but it's coming.
I can't jump yet, but it's coming.
In fact it's all coming.

It just takes time.

PATRICK O'TOOLE

A fighter
Prepared to have a go
Much of the time he will work on his own
Has achieved his goal of walking
Constantly trying to improve walking
Tolerates people asking him to repeat conversation
His ridden a bike!
Played table tennis on Tuesday
Swims on own including underwater
Can swim like a fish
Demonstrates enthusiasm
Great insight into his difficulties
Determined to exercise choice - Great sense of self
Sense of humour - in spite of difficulties
Very caring
Great inner strength
A very humorous and sensitive person
Gentle
A rogue!

THE STAFF AT THE REHABILITATION UNIT

I WAS TRAINED TO BE A NURSE AND I AM GOING BACK

It's only these last few days I've been able to say that but now I know I am going back.

BEST COPY AVAILABLE

Portfolio 2. Sarah : Case-study D

C.V.

NAME	SARAH RICHARDSON
BIRTHDAY	OCTOBER 17
AGE	25
ADDRESS	34 DEARNLEY LANE DONGALTON
WORK	THE McHUGH DAY CENTRE !
HOBBIES	COLLECTING BADGES/POSTCARDS

LEISURE TIME

SARAH

I like to do a lot of competitions and although I don't win many, I enjoy entering them. I have just entered one in the magazine called 'More!' which was for it's 1st birthday.

I also enjoy doing word searches and have entered one of these as a competition.

I have done a lot of macrame, and have made several hanging baskets which then go to the pottery room to have plant pots put in them.

I really enjoy dancing to all sorts of music, and like to go to the Posse disco. I like to dance with my friend Natalie when she comes down to the disco at the Daycentre.

I would really like to travel, especially to Australia to visit my sister. If I go, I would like also to see my sister's children Belinda and Damian. I wish I could win a lot of money so that I could go.

ABOUT OURSELVES

SARAH

The most enjoyable thing that has happened to me in the past year

Two things : going out with my brother and my sister giving me a birthday party

In 1 year's time I expect to be

Form a close relationship with someone (boyfriend)

One thing I would like to change about myself

Being able to go down stairs quicker without worrying

The most important person in my life

Myself

The worst thing that has happened to me

Having accident "I got run over"

At the Day Centre I have learnt to do:-

Factory work

Sewing

reading-writing

These are all skills that I have.

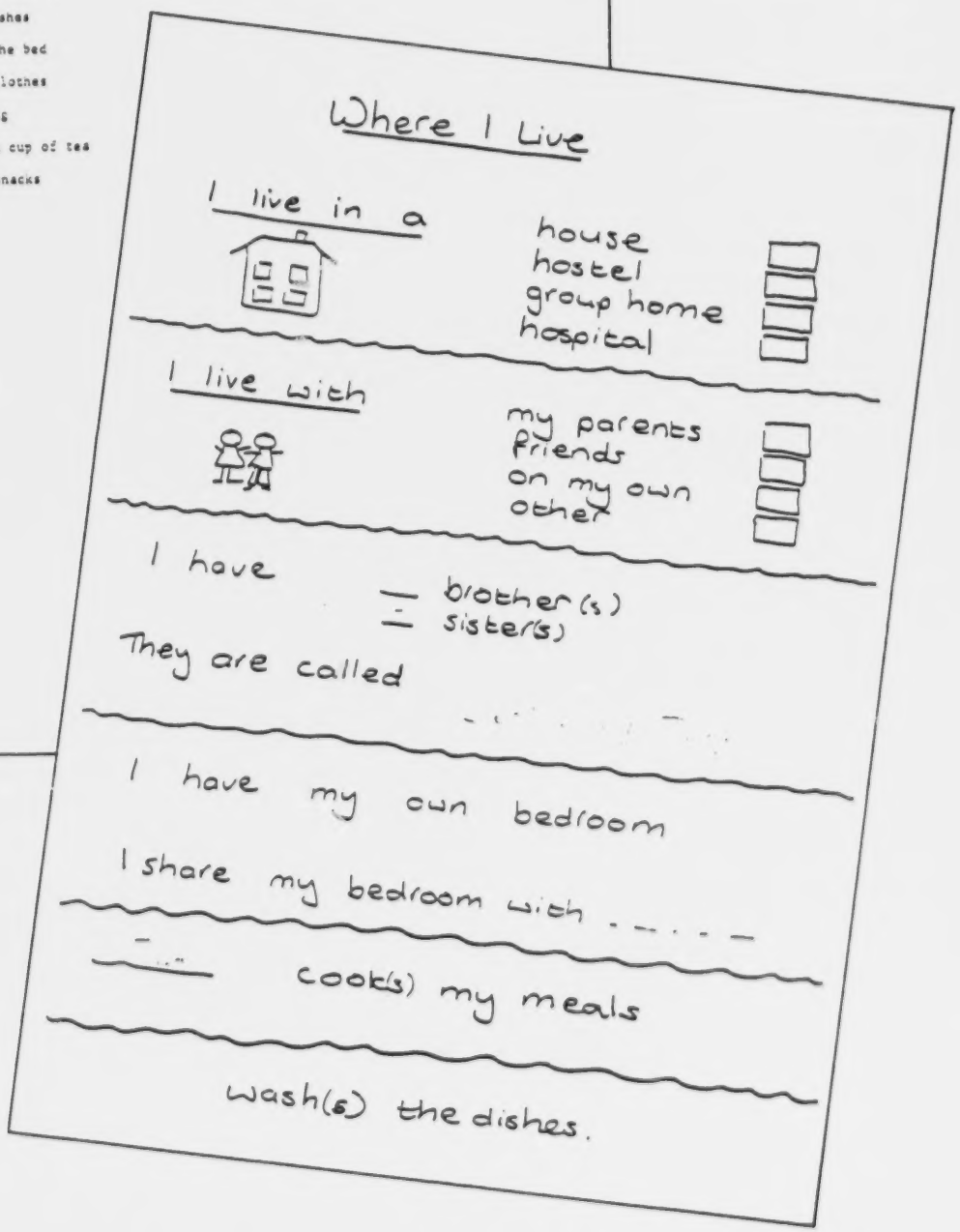
BEST COPY AVAILABLE

SARAH RICHARDSON

Skills I have around the house

At home, I can -

Wash dishes up
Dry dishes
Make the bed
Wash clothes
Ironing
Make a cup of tea
Make snacks
Dust



My Bedroom

1. My room is large medium small ?

2. I share my bedroom with nobody else

. yes . . . .

3. The carpet is [illegible]

4. The walls are [illegible]

5. The curtains are [illegible]

6. What I like about my room is

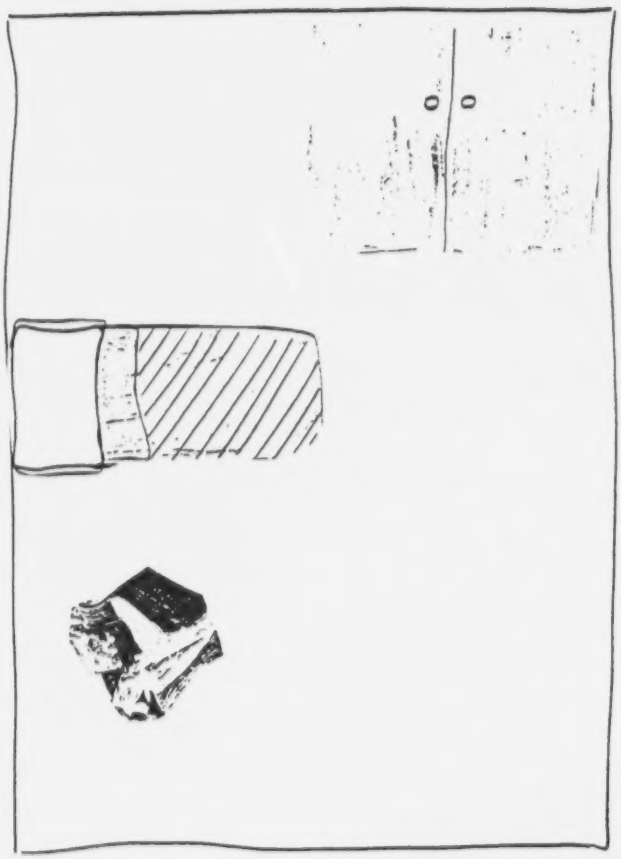
I like my room.

What I don't like about my room is —

[illegible]

My Bedroom
In my big bedroom, I would like a colour telly, a record player, a radio, a bed.
The walls would be pink, the curtains white with pink roses on, and the carpet would be a pastel colour.

My Bedroom



The walls would be [illegible]

The curtains would be [illegible]

I'd also have . . . . .

student

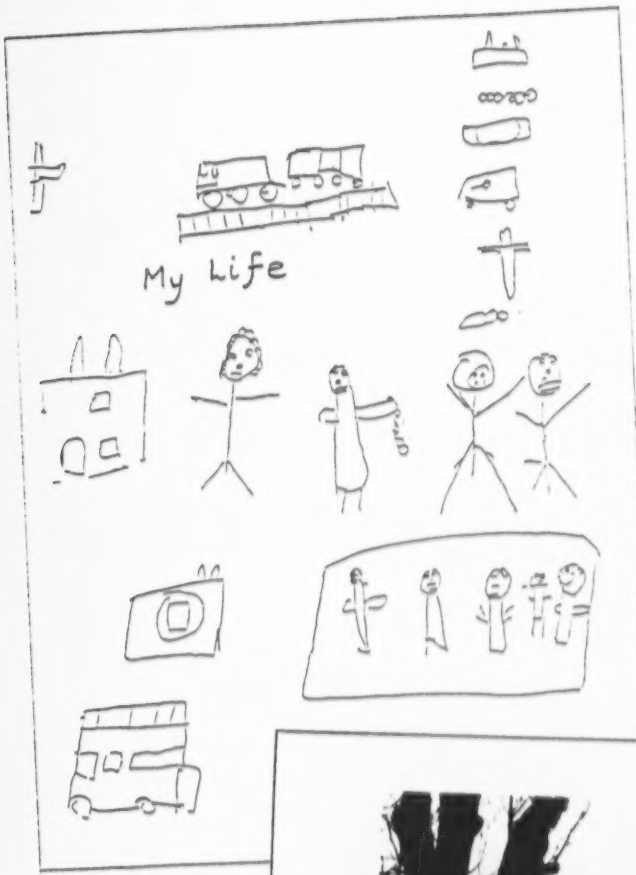
British

Kate

55

Portfolio 3. Stuart : Case-study C

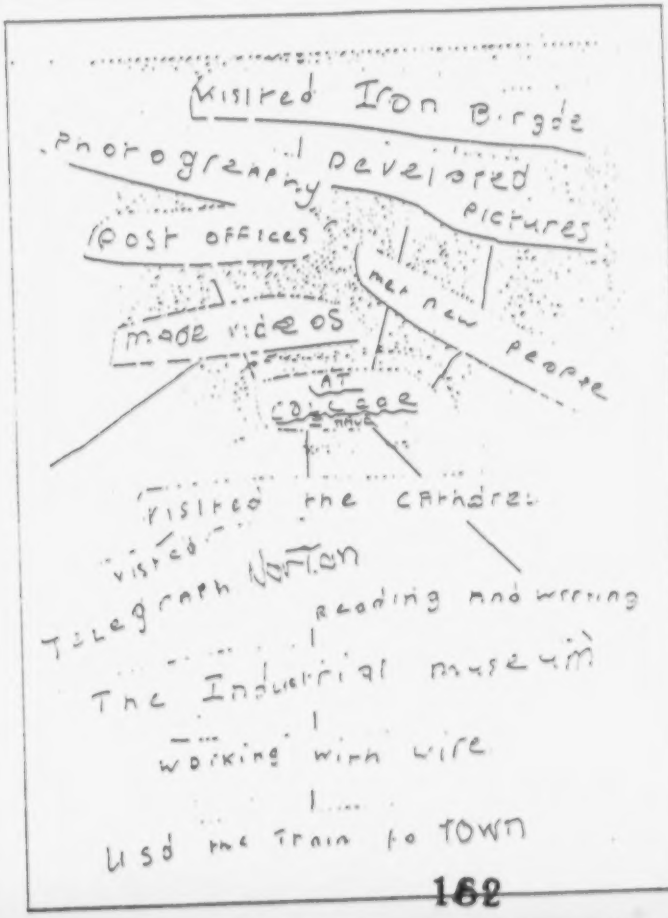
NAME	STUART BROWN
ADDRESS	WEST WARD, THE HOSPITAL, 9 CLAPHAM STREET, NORTON
DATE OF BIRTH	5 MARCH 196[illegible]
HOBBIES	COLLECTING MODEL CARS, TRAINS



The church

mansion 161

TRAVEL ON MY OWN
Read
TALK
write
use a telephone
use a computer
I CAN
help people
good with numbers
be a leader
be reliable
pass on messages
organise


visited Iron Bridge
photography
developed pictures
post offices
met new people
made videos
visited the Cathedral
visited Telegraph Museum
reading and writing
The Industrial museum
working with wire
used the train to town

IN MY EARLY LIFE MY FRIEND WAS CLIVE FOX.
WE WENT TO THE SAME SCHOOL WHICH WAS
ST JOHN'S SCHOOL. I STAYED THERE UNTIL
I WAS 13. THEN I WENT TO THE MANOR. I
STAYED THERE FOR TWO WEEKS BECAUSE I DID NOT
LIKE IT. THEN I CAME TO THE HOSPITAL. I
CAN'T REMEMBER MUCH ABOUT THE FIRST DAY.
I WAS NOT VERY WELL AT THE TIME. I REMEMBER
BEING ANGRY THAT I HAD NO CHOICE IN BEING THERE.
I WAS PUT IN SECLUSION WHEN I FIRST CAME. I
HAVE HAD SOME GOOD TIMES IN THE HOSPITAL DOING
ON TRIPS AND I HAVE MADE FRIENDS WITH SUSAN
BUT MANY PEOPLE HAVE LEFT.

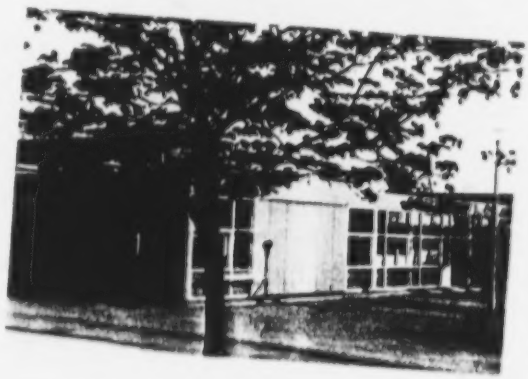
WORK EXPERIENCE

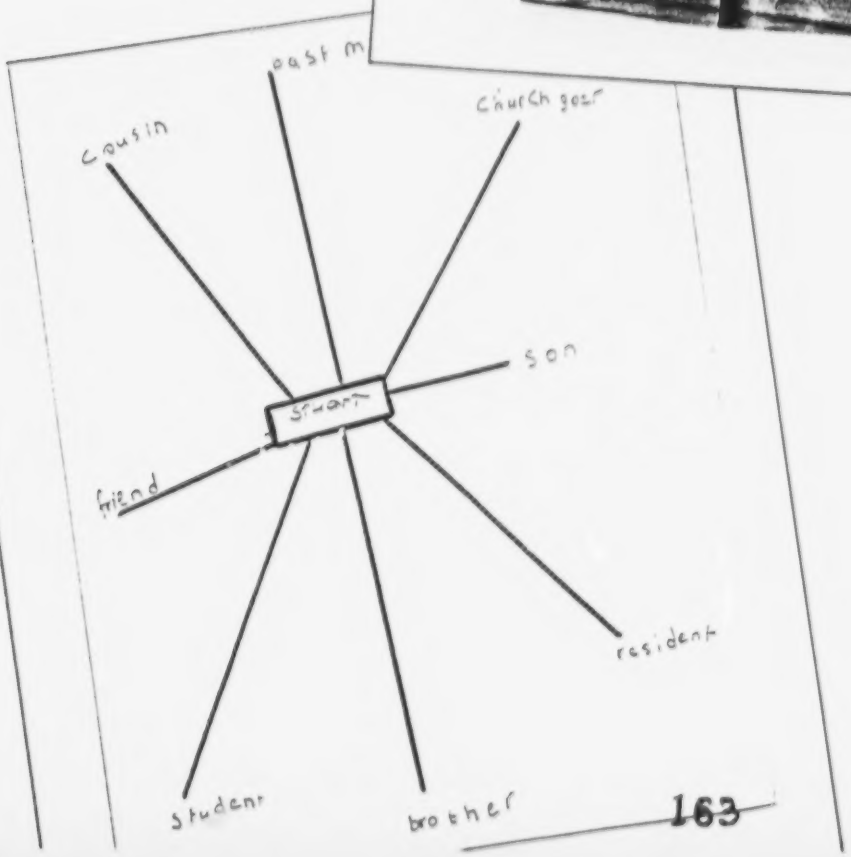
OT Centre

EVERY DAY I ATTENDED OT CENTRE AT THE HOSPITAL
TO MAKE SHELVING TABLES AND DRESSINGS FOR THE
GENERAL HOSPITAL. I LEARNT TO SANDPAPER AND
USE SOME OF THE TOOLS. WE SOLD THE FURNITURE
WE MADE.

Mail

FROM 1985-1988 I DELIVERED THE MAIL ON THE
HOSPITAL SITE. I STARTED AT 8.30 SEVEN DAYS
A WEEK. I PICKED UP THE MAIL FROM THE MAIN
OFFICE AND SECURED IT TO ALL THE WARDS. I
DELIVERED THE AFTERNOON MAIL TOO. I ENJOYED
THIS WORK BUT IT STOPPED BECAUSE I WENT TO
COLLEGE.





Bibliography

Anderson, E.M. *et al. Disability in Adolescence*, Methuen, 1982

Arora, R. and Jinkinson, R. *Black Perspectives on FE Provision*, FEU, 1985

Audit Commission, *Making a Reality of Community Care*, HMSO, 1986

Baldwin, *The Costs of Caring*, 1985

Ball, M. *In Our O n Right: Beyond the Label of Physical Disability*, Community Service Volunteers, 1986

Bicklen, D. 'Advocacy Comes of Age' in *Exceptional Children* Vol.1, no.1, March 1976

Boswell, D.M. and Wingrove, J.M. (eds.), 1974, *The Handicapped Person in the Community*, Open University/Tavistock, 1974

Brandes, D.

Brandon, D., 'Hard Journey Home' in *Social Work Today*, Vol. 14, no.20, 23 Jan. 1983

Brandt, G., John, G. and Pursani, N. *Black Students and Access to Higher Education: Summary of a Feasibility Study*, FEU, 1987

British Psychological Society *Partnership, Participation and Power: Brief Report*, British Psychological Society, 1989

B kley, A. 1986, *Developing Senses: A Practical Guide to Creative Group Work*, CMH, 1986

Campling, J. (ed.), *Images of Ourselves, Women with Disabilities Talking*, Routledge and Kegan Paul, 1981

Canfield, J. and Wells, H. *100 Ways to Enhance Self-Concept in the Classroom*, Prentice-Hall, 1976

Card, H. 'What Will Happen When We're Gone?' in *Community Care*, 28 July 1983

Chadwick, A. and Legge, D. *Curriculum Development in the Education of Adults*, FEU, 1984

Chamberlin, J. *On Our Own*, MIND, 1988

Chapman, L. 'Disabling Services' in *Educare*, No. 31, June 1988

Charnley, A.H. *et al. Care in the Community: Adult and Continuing Education and Joint Finance*, NIACE, 1987

Cockram, L. and Beloff, H. *Rehearsing to be Adult*, National Youth Bureau, 1976

Cooper, D. and Hersov, J. *We Can Change the Future: A Staff Training Resource on Self-Advocacy for People with Learning Difficulties*, National Bureau for Handicapped Students (Skill), 1986

Crawley, B. *The Growing Voice: A Survey of Self-Advocacy Groups in Adult Training Centres and Hospitals in Great Britain*, CMH, 1988

Dearling, A. and Armstrong, H. *The Youth Games Book*, ITT Centre, Renfrewshire, 1980

Dee, L. 1988, *New Directions: A Curriculum Framework for Students with Severe Learning Difficulties*, FEU/NFER, 1988

DES, *A Special Professionalism: Report of the FE Special Needs Teacher Training Working Group*, HMSO, 1987

DHSS *Disabled Person (Services, Consultation and Representation) Act*, HMSO, 1986

DHSS, *Progress in Partnership: Report of the Working Group on Joint Planning*, HMSO, 1985

DHSS, *Draft Guidance Circular on Joint Planning and Collaboration between the NHS, Local Government and Voluntary Organisations*, HMSO, 1986

Donovan, J. *Experiences of a Changing Kind*, MIND/WEA, 1985

Egan, G. and Cowan, M.A. *Moving into Adulthood: Themes and Variations in Self-Directed Development for Effective Living*, 1980

EMFEC, *Planning to Meet Special Educational Needs in Further Education: A Conference Report*, 1989

Evans, N. *Assessing Experiential Learning*, FEU, 1987

FEU, *Access to the Mainstream Curriculum*, 1988

FEU, *Adults with Special Needs:A curriculum Perspective*, 1987

FEU, *Black Perspectives on FE Provision*, 1985

FEU, *Changing the Focus:Women and FE*, 1985

FEU, *A College Guide: Meeting Special Educational Needs*, 1986

FEU, *Curriculum Development for a Multicultural Society: Policy and Curriculum*, 1985

FEU, *Developing Life and Social Skills*, 1983

FEU, *Flexible Learning Opportunities and Special Educational Needs*, 1988

FEU, *Planning a Curricular Response*, 1989

FEU, *Quality in NAFE*, 1987

FEU, *Routes to Coping*, 1984

FEU, *Skills for Living*, 1982

FEU, *Special Needs Occasional Papers*, 1986:

1. *Skills and Self-Confidence*
2. *Opening the Door*
3. *Open and Accessible*

FEU, *Towards an Educational Audit*, 1989

Fiedler, B. *Living Options Lottery, Housing and Support Services for People with Severe Physical Disability 1986/88*, Prince of Wales Advisory Group on Disability, 1988

Fish J. *Descriptions, Definitions and Directions: Special Needs Occassional Paper No.7* FEU, 1989

Fish, J. *Young People with Handicaps: The Road to Adulthood*, OECD/CERI, 1986

Frankish, P. 'Driving out Fear' in *Community Living*, October 1988

Fraser, L. and Ward, K. *Education for Everyday Living*, NIACE/REPLAN, 1988

George, A. and J. 'Democracy Rules' *in Nursing Mirror*, Vol. 159, No.14, 17 October 1984

Gibbs, G. *Learning by Doing*, FEU, 1988

Glendinning, V. *Unshared Care*, Routledge and Kegan Paul, 1983

Goffman, I. *Asylums*, Penguin, 1968

Goffman, I. *The Presentation of the Self in Everyday Life*, Penguin, 1971

Goffman, I. *Stigma*, Penguin, 1968

Griffiths, M. *Enabled to Work: Support into Employment for Young People with Disabilities*, FEU, 1989

Griffiths, R. *Community Care: An Agenda for Action*, HMSO, 1988

Groombridge, J. *Learning for a Change: Reports from REPLAN*, NIACE, 1987

Hall, V. *NCVQ and FE, Coombe Lodge Report*, Vol.20, No.5, FESC, 1987

Harper, G. 'Consumer-led Service Planning' in *Community Living*, March/April, 1988

HMI, *Students with Special Needs in Further Education: Education Observed 9*, Department of Education and Science, 1989

Hinman, J. and Hollingsworth, M. *Tutor Pack: For Those Working with Adult Students on The Assessment of Prior Experiential Learning*, FHE Curriculum Development, ILEA, Westminster College, London

Hutchinson, D. and Tennyson, C. *Transition to Adulthood*, FEU, 1986

Johnston, R. *Exploring the Educational Needs of Unwaged Adults*, NIACE/ REPLAN, 1987

Kelly-Laine, K. *Disabled Youth: The Right to Adult Status*, OECD/CERI, 1988

Kyle, J.G. and Pullen, G. 'Cultures in Contact: Deaf and Hearing People' in *Disability, Handicap and Society*, Vol.3, No.1, 1988

Lavender, P. *Care and Education in the Community: Special Needs Occasional Paper 6*, FEU, 1988

Lavender, P. 'Where Adult Education Fits In' in *Nursing Times*, 31 July 1985

Langham, M. and Parker, V. *Counselling Skills for Teachers*, Framework Press, 1989

Lawrence, R. *Volunteers as Advocates*, The Volunteer Centre, Berkhampstead, 1982

Lloyd, C. *A Realistic Goal? The Integration of Learners with Special Needs into Adult Education: Special Needs Occasional Paper 5*, FEU, 1987

Males, J. 'Safeguarding the Rights and Interests of Mentally Handicapped People' in *Nursing*, Vol.2, No.33, May 1985

McDonald, J. *Education for Unemployed Adults: Problems and Good Practice*, DES/REPLAN, 1984

Milroy, A. and Henney, R. *Changing Our Ways: Steps Towards Redundancy*, Tontine Road Centre, Chesterfield, 1985

Mittler, P. and McConachie, H. (eds.) *Parents, Professionals and Mentally Handicapped People*, Croom Helm, 1983

Mohr, J. *Whatever You Decide: A Workbook for Teaching People Who Are Mentally Retarded on How to Make Choices and Assert Themselves*, Advocating Change Together, Minneapolis, 1983

Murgatroyd, S. *Counselling and Helping*, British Psychological Society and Methuen, 1985

NCVQ *Access and Equal Opportunities in Relation to National Vocational Qualifications: Information Leaflet No.3*, January 1989

Nelson-Jones R. *Practical Counselling Skills*, Holt, Rinehart and Winston, 1983

Nieto, J. and Li, M. *Portfolio Preparation for Young People 16+: A Discussion Document*, FHE Curriculum Development Project, Westminster College, 1987

Notts. Coalition of Disabled People *The Voice of the Disabled*, 5th Edition.

Oliver, M. *Social Work with Disabled People*, Macmillan Education, 1983

O'Brien, J. *The Principle of Normalisation: A Foundation for Effective Services*, CMH, 1981

Paine, N. (ed.), *Open Learning in Transition: An Agenda for Action*, National Extension College, 1988

Parrish, A. 'Residents' Councils' in *Nursing Mirror*, Vol.158, No.18, 2 May 1984

Pitt, M. 'Client Choice and Self-Determination' in *Care in the Community Newsletter*, No.7, Autumn 1987

People First of Washington, *American Self-Advocacy Pack*, CMH, 1986

Prince of Wales Advisory Group on Disability, *Learning Options: Guidelines on Provision of Further and Continuing Education for People with Disabilities*, 1988

Prutzman, P. *et al*, *Friendly Classroom for a Small Planet*, Avery, New Jersey, 1978

Renshaw, J. 'The Challenge of Enabling the Client to be a Consumer' in *Social Work Today*, 27 July 1987

REPLAN, *Adult Learners with Special Needs: Conference Report*, April 1986

REPLAN, *Consulting Women: Educational Initiatives with Unwaged Women*, NIACE, 1987

REPLAN, *Working with Women 1*, NIACE, 1987

REPLAN, *Working with Women 2*, NIACE, 1988

Richardson, A. and Ritchie, J. *Letting Go: Dilemmas for Parents Whose Son or Daughter Has a Mental Handicap*, Open University, 1989

Richardson, A. and Ritchie, J. *Making the Break: Parents' Views About Adults with Mental Handicap Leaving the Parental Home*, King Edward's Hospital Fund for London, 1986

Rogers, C. *Freedom to Learn for the 1980s*, Macmillan, 1983

Roskies, E. *Abnormality and Normality: The Mothering of Thalidomide Children*, Cornell University Press, 1972

Sang, B. *Citizen Advocacy in the UK: A First Attempt*, 1983

Sang, B. and O'Brien, J. *Advocacy: The UK and American Experience*, Kings Fund, 1989

Shearer, A. *Disability - Whose Handicap?* Basil Blackwell, 1981

Stanley, K. 'In-Patients' Human Rights' in *Nursing Mirror* Vol.160, No.3, 16 January 1985

Stowell, R. *Catching Up: Provision for Students with Special Educational Needs in Further and Higher Education*, National Bureau for Handicapped Students, (Skill), 1987

Sutherland, A. *Disabled We Stand*, Souvenir Press, 1981

Thomas, A.P. 'Meeting the Needs of Young Adults with Physical Disabilities' in *Educare*, No.31, June 1988

Two-Can Project *AIDS: Don't Die of Ignorance*, Rycote Centre for the Deaf, Parker Street, Derby DE1 3HF, 1988

Two-Can Project, *Contraception*

Two-Can Project, *Looking for a Home*, 1985

Thomas, D. *The Experience of Handicap*, Methuen, 1982

Walker, A. *Disadvantage and Discrimination: The Fate of the Handicapped School Leaver*, 1985

Walker, A. *Unqualified and Underemployed: Handicapped Young People and the Labour Market*, Macmillan, 1982

Walsh, P. 'Speaking Up for the Patient' in *Nursing Times*, 1 May 1985

Warnock, M. *The Report of the Committee of Enquiry into the Education of Handicapped Children and Young People*, HMSO, 1978

Watts, A.G. and Knasel, E.G. *Adult Employment and the Curriculum*, FEU/ Replan, 1985

Welter, B *et al*, 'Purpose and Philosophy of a Self-Advocacy Organisation' in *Self-Advocacy: A Basic Right*, Kansas University Affiliated Facility, Lawrence, Kansas, 1978

Wertheimer, A. *According to the Papers: Press Reporting on People with Learning Difficulties*, CMH, 1988

Wertheimer A, *Self-Advocacy and Parents: The Impact of Self-Advocacy on the Parents of Young People with Disabilities*, part of the *Working Together?* series, FEU, 1989

Williams, P. and Shoultz, B. *We Can Speak for Ourselves*, Souvenir Press, 1982

Williams, P. 'Attitudes and Perceptions of Others by Mentally Handicapped People', Paper given to the International Cerebral Palsy Society's Seminar 'Idealism and Reality - Mental Handicap in the 1980s', University College, Oxford, 5-9 April 1978

Winkler, F. 'Consumerism in Health Care: Beyond the Supermarket Model' in *Policy and Politics*, Vol.15, No.1, 1987

Wolfensberger, W. *Reflections on the Status of Citizen Advocacy*, National Institute of Mental Retardation, Canada, 1983

Wolfensberger, W. and Thomas, S. *PASSING: Programme Analysis of Service Systems Implementation of Normalisation Goals*, National Institution of Mental Retardation, Canada, 1983

Wolfensberger, W. and Zauna, H. (eds.), *Citizen Advocacy and Protective Services for the Impaired and Handicapped*, National Institute of Mental Retardation, Canada, 1983

Worrell, B. *Advice for Advisors*, National People First, Ontario, 1988